BMJ Open

Comparative end-of-life communication and support in hospitalized decedents before and during the COVID-19 pandemic: a retrospective regional cohort study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-062937
Article Type:	Original research
Date Submitted by the Author:	17-Mar-2022
Complete List of Authors:	Lawlor, Peter; Bruyere Research Institute, Palliative Care; University of Ottawa, Division of Palliative Care, Department of Medicine Parsons, Henrique; University of Ottawa, Division of Palliative Care, Department of Medicine; Ottawa Hospital, Medicine Adeli, Samantha ; University of Ottawa Besserer, Ella; University of Toronto Cohen, Leila; University of Ottawa, Division of Palliative Care, Department of Medicine; Queensway Carleton Hospital, Medicine Gratton, Valérie; University of Ottawa, Division of Palliative Care, Department of Medicine; University of Ottawa, Medicine Murphy, Rebekah; University of Ottawa, Division of Palliative Care, Department of Medicine; Queensway Carleton Hospital, Medicine Warmels, Grace; University of Ottawa, Division of Palliative Care, Department of Medicine; Queensway Carleton Hospital, Medicine Bruni, Adrianna; University of Ottawa, Division of Palliative Care, Department of Medicine; Queensway Carleton Hospital, Medicine Kabir, Monisha; Bruyere Research Institute, Palliative Care Noel, Chelsea; University of Ottawa, Psychology; Bruyere Research Institute, Heidenger, Brandon; Bruyere Research Institute, Palliative Care Anderson, Koby; Bruyere Research Institute, Palliative Care Arsenault-Mehta, Kyle; University of Ottawa, Psychiatry Wooller, Krista; Ottawa Hospital; University of Ottawa Department of Medicine Lapenskie, Julie; Bruyère Research Institute; Ottawa Hospital Research Institute Webber, Colleen; Bruyere Research Institute, ; Ottawa Hospital Research Institute, Bedard, Daniel; Institut du Savoir Montfort, Enright, Paula ; Ottawa Hospital, Division of Palliative Care, Department of Medicine; University of Ottawa Department of Medicine Desjardins, Isabelle; Ottawa Hospital General Campus, Medicine; University of Ottawa Department of Medicine Bhimji, Khadija; University of Ottawa, Division of Palliative Care, Department of Medicine; Queensway Carleton Hospital, Medicine Dyason, Claire; University of Ottawa, Division of Palliative Care, Department of Medicine; Ottawa Hospital Iyengar , Akshai ; University of Ottawa, Medicine; Queensway Carleton Hospital, Medicine

	Bush, Shirley H.; University of Ottawa, Division of Palliaitve Care, Department of Medicine; Bruyere Research Institute, Isenberg, Sarina; Bruyère Research Institute; University of Ottawa, Division of Palliative Care, Department of Medicine Tanuseputro, Peter; Ottawa Hospital Research Institute; Bruyère Research Institute Vanderspank-Wright, Brandi; University of Ottawa Faculty of Health Sciences, School of Nursing; Ottawa Hospital Research Institute, Downar, James; University of Ottawa, Divisions of Palliative Care and Critical Care, Department of Medicine; Bruyere Research Institute
Keywords:	COVID-19, GENERAL MEDICINE (see Internal Medicine), Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Adult intensive & critical care < INTENSIVE & CRITICAL CARE, Adult palliative care < PALLIATIVE CARE, GERIATRIC MEDICINE

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Comparative end-of-life communication and support in hospitalized decedents before and during the COVID-19 pandemic: a retrospective regional cohort study

Peter Lawlor MB FRCPI MMedSc

Senior Investigator, Bruyère Research Institute

Clinician Investigator, Ottawa Hospital Research Institute,

Professor, Division of Palliative Care, Dept of Medicine, University of Ottawa

plawlor@bruyere.org

ORCID ID: 0000-0001-7319-1395 [Corresponding Author]

Henrique Parsons MD MSc

Clinician Investigator, Ottawa Hospital Research Institute, Bruyère Research Institute

Associate Professor, Division of Palliative Care, Department of Medicine, University of Ottawa

hparsons@toh.ca

Samantha Rose Adeli RD

MS2, Class of 2024, Faculty of Medicine, University of Ottawa

sadel029@uottawa.ca

Ella Besserer

Physician Assistant Student Y2, The University of Toronto Class of 2022

ellabesserer@gmail.com

Leila Cohen MD

Palliative Care Physician, Department Medicine, The Ottawa Hospital

lecohen@toh.ca

Valérie Gratton MD

Palliative Care Physician, Montfort Hospital

Clinical Researcher, Institut du Savoir Montfort

Assistant Professor, Division of Palliative Care, Department of Medicine, University of Ottawa

valeriegratton@montfort.on.ca

Rebekah Murphy MD

Palliative Care Physician, Department Medicine, The Ottawa Hospital

RMurphy@bruyere.org

Grace Warmels BA MD CCFP(PC)

Palliative Care Physician, Department Medicine, The Ottawa Hospital

Clinician Investigator, Ottawa Hospital Research Institute; Lecturer, Division of Palliative Care, Department of Medicine, University of Ottawa

gwarmels@toh.ca

Adrianna Bruni MD

Palliative Care Physician, Department Medicine, The Ottawa Hospital

adbruni@toh.ca

Monisha Kabir

Research Associate, Bruyère Research Institute

mkabir@bruyere.org

Chelsea Noel

Research Coordinator, Bruyère Research Institute

chelseaannenoel@gmail.com

Brandon Heidinger

Research Coordinator, Bruyère Research Institute

bheidinger@bruyere.org

Koby Anderson

Research Assistant, Bruyère Research Institute

KAnderson@bruyere.org

Kyle Arsenault-Mehta MD

PGY4 Resident in Psychiatry, University of Ottawa

karse056@uottawa.ca

Krista Wooller MD

Physician, Department of Medicine, The Ottawa Hospital

Assistant Professor, University of Ottawa

krwooller@toh.ca

Julie Lapenskie MScAH

Research Associate and Manager, Ottawa Hospital Research Institute and Bruyère Research Institute

JLapenskie@bruyere.org

Colleen Webber PhD

Senior Research Associate, The Ottawa Hospital Research Institute

cowebber@ohri.ca

Daniel Bédard MSc

Research Associate, Institut du Savoir Montfort

danielbedard@montfort.on.ca

Paula Enright MD

Palliative Care Physician, Department of Medicine, The Ottawa Hospital

Assistant Professor, Division of Palliative Care, Department of Medicine, University of Ottawa

penright@toh.ca

Isabelle Desjardins MD

Clinician Educator, Department of Medicine, University of Ottawa

idesjardins@toh.ca

Khadija Bhimji MSc MD FRCPC

Palliative Care Physician, Queensway Carleton Hospital

Assistant Professor, Division of Palliative Care, Department of Medicine, University of Ottawa

KBhimji@toh.ca

Claire Dyason MD

Palliative Care Physician, Department of Medicine, Queensway Carleton Hospital

Lecturer, Division of Palliative Care, Dept of Medicine, University of Ottawa

cdyason@toh.ca

Akshai Iyengar MSc MD FRCPC

Medical Director, Department of Critical Care Medicine, Queensway Carleton Hospital

Assistant Professor, University of Ottawa

aiyengar@qch.on.ca

Shirley H Bush MBBS DRCOG DCH MRCGP PgDip Pall Med FAChPM

Clinician Investigator, Ottawa Hospital Research Institute and Bruyère Research Institute

Associate Professor, Division of Palliative Care, Dept of Medicine, University of Ottawa sbush@bruyere.org

ORCID ID: 0000-0001-8907-1283

Sarina Isenberg MA PhD

Bruyère Chair in Mixed Methods Palliative Care Research, Bruyère Research Institute

Assistant Professor, Division of Palliative Care, Department of Medicine, University of Ottawa

Assistant Professor, Department of Family and Community Medicine, University of Toronto

sisenberg@bruyere.org

ORCID ID: 0000-0001-6059-5366

Peter Tanuseputro MD

Scientist, Clinical Epidemiology Program, Ottawa Hospital Research Institute

Investigator, Bruyère Research Institute, Assistant Professor, Division of Palliative Care, Dept of Medicine, University of Ottawa

ptanuseputro@toh.ca

Brandi Vanderspank-Wright PhD RN CNCC(C)

Associate Professor, Faculty of Health Sciences, School of Nursing, University of Ottawa

Affiliate Investigator, Ottawa Hospital Research Institute

bvanders@uottawa.ca

ORCID ID: 0000-0002-1908-8212

James Downar MDCM MHSc

Professor, Head of the Division of Palliative Care, Department of Medicine, University of Ottawa

Department of Palliative Care, Élisabeth Bruyère Hospital

jdownar@toh.ca

Corresponding Author Details:

Dr Peter G Lawlor,

Dept of Palliative Care,

Bruyère Continuing Care,

43 Bruyère Street,

Ottawa,

Ontario

Canada K1N 5C8

Email: plawlor@bruyere.org

Tel: +16135626262

Fax: +16135626371

ABSTRACT

Objective

To compare end-of-life in-person family presence, patient-family communication and healthcare team-family communication encounters in hospitalized decedents before and during the COVID-19 pandemic.

Design

In a regional multicentre retrospective cohort study, electronic health record data were abstracted for a pre-pandemic group (Pre-COVID) and two intra-pandemic (March-August 2020, Wave 1) groups, one COVID-19-free (COVID-ve) and one with COVID-19 infection (COVID+ve). Pre-COVID and COVID-ve groups were matched 2:1 (age, sex and care service) with the COVID+ve group.

Setting

One quaternary and two tertiary adult, acute care hospitals in a large urban region.

Participants

Decedents (N=425): COVID+ve (n=85), COVID-ve (n=170) and Pre-COVID (n=170).

Main outcome measures

End-of-life (last 48 hours) in-person family presence and virtual (video) patient-family communication, and end-of-life (last 5 days) virtual team-family communication encounter occurrences were examined using logistic regression with odds ratios (ORs) and 95% confidence intervals (CIs). End-of-life (last 5 days) rates of in-person and telephone team-family communication encounters were examined using mixed-effects negative binomial models with Incidence rate ratios (IRRs) and 95% CIs.

Results

End-of-life in-person family presence decreased progressively across Pre-COVID (90.6%), COVID-ve (79.4%) and COVID+ve (47.1%) groups: adjusted ORs=0.38 (0.2-0.73) and 0.09 (0.04-0.17) for COVID-ve and COVID+ve groups, respectively. COVID-ve and COVID+ve groups had reduced in-person but increased telephone team-family

communication encounters: IRRs=0.76 (0.64-0.9) and 0.61 (0.47-0.79) for in-person, and IRRs=2.6 (2.1-3.3) and 4.8 (3.7-6.1) for telephone communications, respectively. Virtual team-family communication encounters occurred in 17/85 (20%) and 10/170 (5.9%) of the COVID+ve and COVID-ve groups, respectively: adjusted OR=3.68 (1.51-8.95).

Conclusions

In hospitalized COVID-19 pandemic Wave 1 decedents, in-person family presence and in-person team-family communication encounters decreased at end-of-life, particularly in the COVID+ve group; virtual modalities were adopted for communication, and telephone use increased in team-family communication encounters. The implications of these communication changes for the patient, family, and healthcare team warrant further study.

Abstract: 300 words

Main manuscript: 3,133 words

Tables: 5

Figures: 1

Appendices: 3

Keywords: COVID-19, pandemic, end-of-life communication, palliative care, critical care, supportive care, interprofessional care, patient-provider communication

Strengths and limitations of this study

- There were no missing data in a decedent cohort that was representative of the source population in all adult acute care hospitals in a large urban region.
- Cohort groups were effectively matched on the basis of age, sex and care service, which enabled valid comparisons to be made.
- In data abstraction, we cannot exclude the possibility of misclassification bias, which could have occurred despite rigorous training and data accuracy checks.
- The retrospective nature of the study and the absence of a qualitative assessment of communication encounters are acknowledged limitations.
- The generalizability of our study findings is largely limited to end-of-life care for hospitalized decedents, whereas many of the COVI-19 pandemic related deaths occurred in nursing homes.

INTRODUCTION

Coronavirus disease 2019 (COVID-19) emerged in late 2019 and became a global pandemic within three months.[1 2] COVID-19 infection is associated with high rates of hospitalization, intensive care unit (ICU) admission, and increased mortality, particularly in older people, the frail and those with chronic medical conditions.[3-5] These metrics underscore the need to integrate a palliative approach that includes shared decision-making, sensitive goals of care discussions respecting patient and family preferences, and meeting the psychosocial and spiritual needs of patients and their families facing a life-threatening illness.[6-8] Communication involving the patient, family and healthcare team triad, particularly in-person, is an integrative component of a proactive palliative approach in non-pandemic times,[8] and highly valued by family members in their subsequent bereavement.[9-11] Moreover, in-person communication is a fundamental human need and inability to say goodbye prior to death of a loved one has been identified as a predictor of complicated grief in bereavement.[12]

The pandemic associated increase in end-of-life care communicative needs has been further compounded by the introduction of strict infection control measures, including visitor restriction and patient isolation policies for hospitalized patients.[13-15] Although mandated from a public health perspective, these measures pose obstacles to end-of-life communication.[11 13 16]

Studies specifically examining end-of-life communication issues during the COVID-19 pandemic have, to date, been mostly qualitative and relatively limited in quantifying these phenomena, or were restricted in focus, such as resuscitation status,[17 18] or reliant on voluntary reporting.[19 20] To address these gaps, we retrospectively examined end-of-life care in relation to the COVID-19 pandemic in adult acute care hospitals in an urban region. We hypothesized that the pandemic-related visitor and isolation restrictions imposed in these hospitals was associated with a reduced number of in-person, face-to-face, healthcare team-family and family-patient communications, and an increase in alternative communication modalities, such as tele- or virtual (video) conferencing. The primary study objective was to examine the impact of COVID-19 status on patient-family and healthcare team-family communication encounters during end-of-life care. We compared those dying pre-pandemically versus those dying during Wave 1 of the pandemic, due to recorded COVID-19 infection itself versus

other causes, without COVID-19 infection. Comparative allied health involvement, palliative medicine consultation and resuscitation order status were examined as additional objectives.

Methods

Study design

We conducted a multicentre retrospective matched cohort study of decedents' documented end-of-life care in adult acute tertiary or quaternary care hospitals. The study is reported in accordance with the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) criteria.[21]

Setting

The source population consisted of inpatients in Ottawa (population 1.4 million), Canada, who died in the city's three adult acute care hospital sites between November 1, 2019 and August 31, 2020. Site 1, The Ottawa Hospital is a quaternary acute care hospital with 1271 inpatient beds. Site 2, The Hôpital Montfort is a tertiary acute care francophone academic hospital with 289 inpatient beds. Site 3, The Queensway-Carleton Hospital is a tertiary acute care hospital with 264 inpatient beds. All sites used established electronic health records (EHR) systems, Epic (Epic Systems Corporation) at Site 1 and MEDITECH (Medical Information Technology, Inc.) at Sites 2 and 3, for documentation of patient care and encounters with family.

Approximately 2487 people were diagnosed with COVID-19 in Ottawa between March 1 and August 31, 2020, of whom 266 died, including 85 in acute care hospitals.[22] Public health measures and restrictions were applied throughout Ontario, including in acute care hospitals, in early March 2020, and remained largely in place until the end of the study period.

The study's key exposures related to COVID-19 infection status during decedents' hospital admission and the timing of the admission in relation to the pandemic. Based on these exposures, 3 study groups were designated: a Pre-COVID group who died prior to the COVID-19 pandemic (deaths occurring between November 1st 2019 and February 29th 2020); and 2 groups whose deaths occurred within the initial, Wave 1 of the pandemic

(March 1st 2020 to August 31st 2020), one without any record of COVID-19 during their hospital admission and the other who died of COVID-19 infection, designated COVID-ve and COVID+ve, respectively.

Participants

Adult (≥ 18 years old) decedents were eligible for inclusion if they died in ICU or under the care of a medical service in the study period. Emergency department decedents and those primarily under surgical care were excluded. The index study group was COVID+ve; all (n=85) of these decedents were included. The Pre-COVID (n=170) and COVID-ve (n=170) group members were matched 2:1 with the COVID+ve members from each site on the basis of age (± 5 years), sex and care service (Medicine or ICU) at the time of death.

Data sources/measurement

Using a common electronic study database across sites, anonymized EHR data, including study variables were abstracted by teams of internal/palliative medicine physicians and two research assistants. All abstractors received training regarding abstraction requirements. Of all patient records, 154 (35%) underwent duplicate abstraction to confirm accuracy of details.

Variables

Study group designation was based on EHR documentation of COVID-19 infection status, date of death and death certification. Demographic variables included age, sex, admission referral source, acute care site, care service at death, and admission duration (days). The association of these variables was examined in relation to the occurrence of patient-family and healthcare team-family communicative encounters. Admission duration was included as a potential confounder, as decedents were not matched on this criterion. Clustering in association with either location or actual presence of family in the last 48 hours was anticipated and adjusted for in multivariable analyses.

Documented family-patient communicative interactions involving physical presence and virtual presence in the last 48 hours of life, were each recorded as outcomes and each treated as binary (Yes/No) variables. The outcomes of documented healthcare team (physician, nursing and allied health)-family interactive encounters

(physical presence, telephone conversations, and virtual presence) in the last 5 days of life, were each recorded as a total count, based on individual note entries in the EHR. In the absence of family, the decedent's substitute decision maker was included within the category of family. The involvement of allied health professionals, palliative medicine consultation and the documented presence of a no cardiopulmonary resuscitation (CPR) order were recorded as binary variables and represented additional indices of end-of-life communication and support.

Patient and public involvement

The retrospectively acquired decedent data in this study is part of an overall project that involves an ongoing prospective evaluation of grief in decedents' bereaved family members. Although there was no direct patient or public involvement in the retrospective component of the project, we engaged with three different knowledge user organizations (Bereaved Families of Ontario, Canadian Virtual Hospice and Champlain Hospice Palliative Care Program), whose representatives collaborated with the study planning team and were co-applicants in funding applications for the overall project.

Ethics

The Research Ethics Boards (REBs) of each hospital approved the study: Ottawa Health Science Network-REB (20200653-01H, December 18th 2020); Montfort REB (20-21-10-032, December 2nd 2020) and Queensway Carleton Hospital REB (20-06, December 1st 2020).

Bias

Data abstractors were not blinded as to the study objectives and consequently misclassification bias cannot be ruled out. Matching variables were included a priori in multivariable models of the main outcomes.

Study size

The sample size was determined by the inclusion of all Wave 1 deaths due to COVID-19 (COVID+ve, n=85) and the subsequent 2:1 matching to generate the other two study groups.

Quantitative variables

Healthcare team-family interactions in the last 5 days of life were treated as count data and summarized as median (interquartile, Q1-Q3 range); other continuous variables were expressed as mean ± standard deviation (SD) unless otherwise indicated.

Statistical methods

Demographic characteristics, allied health involvement, palliative medicine consultation and resuscitation order status were compared among study groups, using a chi-square test for categorical variables, and an ANOVA or Kruskal-Wallis test for continuous variables, as appropriate. The presence of family was reported using unadjusted and adjusted multivariable logistic regression, reporting odds ratios (ORs) and corresponding 95% confidence intervals (CIs). The comparison of virtual patient-family encounters was restricted to the intra-pandemic groups, as these encounters were rarely documented pre-pandemically. The count distribution of healthcare team-family in-person **(Appendix 1)** and telephone interactions **(Appendix 2)** were zero inflated and overdispersed, with potential clustering both by site and family presence in the last 48 hours of life. Consequently, mixed effects negative binomial models were used, including site and family presence in the last 48 hours as random effects and reporting incidence rate ratios (IRRs) with 95% CIs for in-person and telephone interactions among the groups. Due to absence of virtual healthcare team-family encounters pre-pandemically, and their infrequent occurrence in the intra-pandemic groups, the initial total counts underwent binary transformation to reflect occurrence or non-occurrence, and group comparison was restricted to the intra-pandemic groups. Stata (StataCorp. 2015. *Stata Statistical Software: Release 14*. College Station, TX: StataCorp LP.) was used for statistical analysis, and statistical significance was set at $p < 0.05$.

Results

Study sample derivation and demographic data

The final study sample of 425 decedents consisted of the Pre-COVID (n=170), COVID-ve (n=170) and COVID+ve (n=85) groups **(Figure 1)**.

<<<< Insert Figure 1 here>>>>

Comparison of demographic data revealed no statistically significant difference among the study groups regarding the matching criteria **(Table 1).**

Table 1 Demographic characteristics among study groups designated according to COVID-19 status

Demographic characteristics	**Time periods and designated study groups**			**P values**
	Nov 2019-Feb 2020	**Mar 2020 – Aug 2020**		
	Pre-COVID Group N=170 (%)*	**COVID-ve Group N=170 (%)***	**COVID+ve Group N=85 (%)***	
Age				
Years, mean ± SD	79.5 ± 12.3	79.2 ± 12.3	78.9 ± 12.2	0.942
Sex				
Male	100 (58.8)	100 (58.8)	50 (58.8)	1.0
Admission referral source				
Home	99 (58.2)	109 (64.1)	31 (36.5)	**<0.001**
Retirement Home	36 (21.2)	34 (20.0)	11 (11.8)	
Nursing Home / Long Term Care	22 (12.9)	8 (4.7)	43 (50.6)	
Complex Continuing Care	2 (1.2)	2 (1.2)	0 (0.0)	
Other	11 (6.5)	17 (10.0)	1 (1.2)	

Care service at death				
Medicine service/unit	118 (69.4)	122 (71.7)	62 (72.9)	0.814
Intensive Care Unit	52 (30.6)	48 (28.2)	23 (27.1)	
Admission duration				
Days, median [Q1-Q3]	6 (2-15)	9 (4-21)	6 (4-13)	0.062
Documented No CPR† order				
Present	160 (94.1)	161 (94.7)	82 (96.5)	0.724
Median days (Q1-Q3) pre- death if order present	3 (1-10)	5 (1-16)	5 (3-11)	0.184

*** Column numbers refer to number of persons (%) in respective study groups unless stated otherwise**

†CPR=cardiopulmonary resuscitation

The overall mean age was 79.3 ± 12.2 and the majority (58.8%) were male. Admission referrals from nursing homes were higher in the COVID+ve (50.6%) group compared to Pre-COVID (12.9%) or COVID-ve (4.7%) groups ($p<0.001$).

Family-patient communication encounters

In the last 48 hours of life, family member presence decreased progressively across the Pre-COVID (90.6%), COVID-ve (79.4%) and COVID+ve (47.1%) groups **(Table 2)**.

Table 2 In-person family presence in the last 48 hours of life and variables examined in logistic regression analyses

Variables examined	Proportion of patients* (%)	Unadjusted OR (95% CI)		P value		Adjusted OR (95% CI)		P value
In-person family presence	329/425 (77.4)							
Age of decedent†	…	0.997	(0.98-1.02)	0.774		0.99	(0.97-1.02)	0.608
Sex of decedent								
Female	139/175 (79.4)	1				1		
Male	190/250 (76.0)	0.82	(0.51-1.31)	0.406		0.75	(0.44-1.26)	0.272
Study group								
Pre-COVID	154/170 (90.6)	**1**				**1**		
COVID-ve	**135/170 (79.4)**	**0.40**	**(0.21-0.76)**	**0.005**		**0.38**	**(0.199-0.73)**	**0.003**
COVID+ve	**40/85 (47.1)**	**0.09**	**(0.05-0.18)**	**<0.001**		**0.09**	**(0.04-0.17)**	**<0.001**
Hospital site								
Site 1	138/170 (81.2)	**1**				**1**		
Site 2	**108/155 (69.7)**	**0.53**	**(0.32-0.89)**	**0.017**		**0.46**	**(0.26-0.84)**	**0.011**
Site 3	83/100 (83.0)	1.13	(0.59-2.17)	0.707		1.15	(0.56-2.34)	0.701
Care service at death								

Medicine	231/302 (76.5)	1				1		
Intensive Care Unit	98/123 (79.7)	1.21	(0.72-2.01)	0.477		0.92	(0.47-1.79)	0.801
Admission duration†	…	1.004	(0.99-1.01)	0.411		1.004	(0.99-1.02)	0.428

*Proportion of patients = proportion of total number for each categorical variable. OR = Odds Ratio;

†Treated as a continuous variable or covariate;

The unadjusted OR for family physical presence in the last 48 hours of life was 0.40 (0.21-0.76) and 0.09 (0.05-0.18) for the COVID-ve (p=0.005) and COVID+ve (p<0.001) groups, respectively, and 0.53 (0.32-0.89) for Site 2 (p=0.017). These findings were maintained with marginal differences in the multivariable model.

In the Pre-COVID group, only two virtual patient-family encounters were documented in the last 48 hours of life, compared to occurrence rates of 31.8% and 10% in the COVID-ve and COVID+ve groups, respectively. In a multivariable model restricted to the intra-pandemic decedents (n=255), the adjusted OR for the occurrence of a virtual encounter was 3.45 (1.67-7.15) and 2.14 (1.01-4.53) for the COVID+ve group (p=0.001) and for absence of a family member in the last 48 hour of life (p=0.048), respectively **(Table 3).**

Table 3 Virtual family presence in the last 48 hours of life and variables examined in logistic regression analyses

Variables examined	**Proportion of patients* (%)**	**Unadjusted OR (95% CI)**		**P value**		**Adjusted OR (95% CI)**		**P value**
Virtual family presence§	44/255 (17.3)							
Age of decedent†	…	1.01	(0.98-1.04)	0.402		1.02	(0.98-1.05)	0.334
Sex of decedent								
Female	19/105 (18.1)	1				1		

Male	25/150 (16.7)	0.91	(0.47-1.75)	0.766		0.88	(0.44-1.80)	0.734
Study group								
COVID-ve	17/170 (10.0)	**1**				**1**		
COVID+ve	27/85 (31.8)	**4.19**	**(2.13-8.25)**	**<0.001**		**3.45**	**(1.67-7.15)**	**0.001**
Hospital site								
Site 1	21/102 (20.6)	1				1		
Site 2	16/93 (17.2)	0.80	(0.39-1.65)	0.548		0.75	(0.33-1.70)	0.486
Site 3	7/60 (11.7)	0.51	(0.20-1.28)	0.152		0.55	(0.21-1.47)	0.235
Care service at death								
Medicine	31/184 (16.9)	1				1		
Intensive Care Unit	13/71 (18.3)	1.11	(0.54-2.26)	0.782		1.44	(0.58-3.53)	0.424
Admission duration†	…	0.997	(0.98-1.01)	0.600		1.001	(0.99-1.01)	0.855
Family present in-person in last 48 hours of life								
Yes	**21/175 (12.0)**	**1**				**1**		
No	**23/80 (28.8)**	**2.96**	**(1.52-5.75)**	**0.001**		**2.14**	**(1.007-4.53)**	**0.048**

*Proportion of patients = proportion of total number for each categorical variable. OR = Odds Ratio;

†Treated as a continuous variable or covariate;

§ Pre-COVID group (n=170) were excluded from the bivariable analyses and the multivariable model.

Healthcare team-family communication encounters

In the last 5 days of life, there was a 15% reduction in physical or in-person healthcare team communication encounters in male decedents compared to females, with IRR=0.85 (0.72-0.99), p=0.041 **(Table 4).**

Table 4 Mixed effects negative binomial models examining number of healthcare team-family communication encounters in the last 5 days of life*

Team-family communication encounters		**Incidence Rate Ratio (95% CI)**		**P value**
Type and variables examined	**Count†**			
In-person encounter	2 (1-4)			
Age of decedent§	…	0.997	(0.99-1.004)	0.396
Sex of decedent (Female)	2 (1-5)	1		
Sex of decedent (Male)	2 (1-4)	**0.85**	**(0.72-0.99)**	**0.041**
Study group; exposure status				
Pre-COVID	3 (2-5)	**1**		
COVID-ve	2 (1-4)	**0.76**	**(0.64-0.90)**	**0.001**
COVID+ve	0 (0-2)	**0.61**	**(0.47-0.79)**	**<0.001**
Care service at death				
Medicine service	2 (0-5)	**1**		
Intensive Care Unit	2 (1-3)	**0.68**	**(0.55-0.84)**	**<0.001**
Days in Hospital§	…	1.003	(0.999-1.006)	0.411

Telephone communications	1 (0-3)			
Age of decedent[§]	…	1.005	(0.996-1.01)	0.283
Sex of decedent (Female)	1 (0-3)	1		
Sex of decedent (Male)	1 (0-3)	1.002	(0.84-1.19)	0.984
Study group; exposure status				
Pre-COVID	1 (0-1)	1		
COVID-ve	2 (1-3)	**2.60**	**(2.09-3.25)**	**<0.001**
COVID+ve	4 (2-5)	**4.77**	**(3.72-6.12)**	**<0.001**
Care service at death				
Medicine	1 (0-3)	1		
Intensive Care Unit	1 (0-3)	1.16	(0.93-1.43)	0.189
Days in Hospital[§]	…	0.998	(0.99-1.001)	0.203

*****Hospital site and family's physical presence in the last 48 hours of life were both included as random effects in both models;

†Counts for categorical variables, median (Q1-Q3);

[§]Treated as a continuous covariate in models.

There was an approximate 24% and 39% reduction in the incidence rate of these communications in the COVID-ve and COVID+ve groups, with IRRs of 0.76 (0.64-0.90) and 0.61 (0.47-0.79), p=0.001 and p<0.001, respectively. Compared to a medicine ward, death in ICU was associated with a 32% reduction in the incidence rate of in-person communications; IRR=0.68 (0.55-0.84), p<0.001.

In the model examining telephone communications between the healthcare team and family members in the last 5 days of life, there was a relative increase in the incidence rate of these communications in the COVID-ve and particularly in the COVID+ve groups, with IRRs of 2.6 (2.09-3.25) and 4.77 (3.72-6.12), p<0.001 for both, respectively.

Virtual healthcare team-family communication encounters occurred in 17 (20%) of the COVID+ve and 10 (5.9%) of COVID-ve decedents (p=0.001). Both COVID+ve status and death in the ICU were associated with an increased occurrence of virtual communication encounters, with unadjusted ORs of 4.0 (1.74-9.18) and 2.29 (1.01-5.18), p=0.001 and p=0.046, respectively **(Appendix 3).** Hospital Site 2 was associated with an unadjusted OR of 0.33 (0.12-0.95), p=0.039, for virtual communication encounters, compared to Hospital Site 1. However, only COVID+ve status had an independent association with virtual communications in a multivariable model, with an adjusted OR of 3.68 (1.51-8.95), p=0.004.

Interprofessional supportive care team involvement

Relative to the Pre-COVID group, with proportions of 41.2%, 45.9% and 30.4% for the respective involvement of physiotherapy, medical social work and occupational therapy during admission, the COVID-ve group had greater involvement (50.6%, 58.2% and 42.9%, respectively), whereas the COVID+ve group had lesser involvement of these disciplines with rates of 22.4%, 30.6% and 12.9%, respectively, p<0.001 for all **(Table 5).**

Table 5 Comparison of interprofessional team member involvement among study groups

Interprofessional team members	**Time periods and designated groups**				**P value**
	Nov 2019-Aug 2020	**Nov 2019-Feb 2020**	**March 2020-August 2020**		
	All Groups N=425 (%)*	**Pre-COVID N=170 (%)***	**COVID-ve N=170 (%)***	**COVID+ve N=85 (%)***	
Physiotherapy	**175 (41.2)**	**70 (41.2)**	**86 (50.6)**	**19 (22.4)**	**<0.001**

Medical Social Worker	**195 (45.9)**	**70 (41.2)**	**99 (58.2)**	**26 (30.6)**	**<0.001**
Spiritual Care	105 (24.7)	49 (28.8)	42 (24.7)	14 (16.5)	0.098
Occupational therapy	**129 (30.4)**	**45 (26.5)**	**73 (42.9)**	**11 (12.9)**	**<0.001**
Palliative Care					
Consult requested	167 (39.3)	70 (41.2)	71 (41.8)	26 (30.6)	0.184
Consult completed	159 (37.4)	67 (39.4)	67 (39.4)	25 (29.4)	0.234
Days from consult completion to death (median, Q1-Q3)	3 (1-7)	4 (1-9)	3 (1-6)	3 (2-12)	0.577

***Column numbers refer to number of persons (%) within respective groups unless stated otherwise**

There were no statistically significant study group differences with respect to spiritual care or palliative care involvement, though the proportion with spiritual care involvement decreased from 28.8% in the Pre-COVID group to 12.9% in the COVID+ve group (p=0.098).

Discussion

Study findings and putative explanations

Our study found reduced physical presence of family at end-of-life for pandemic decedents, particularly in those dying with COVID-19 infection, with a reduction of almost 50% when compared to matched pre-pandemic controls. Although we adjusted for family presence at end-of-life, we found a reduced incidence rate of in-person healthcare team-family meetings in the last 5 days of life, most notably in the COVID+ve group, but also in male decedents and those dying in ICU, when compared to matched pre-pandemic controls. It is unclear if the matching

process contributed to this finding in male decedents, whereas reduced in-person healthcare team-family encounters have previously been reported in ICU during the COVID-19 pandemic.[23]

The reductions in both types of in-person encounters in our study occurred in the context of pandemic-related patient isolation policies and visitor restrictions. Although visitor restrictions were introduced, there were efforts to make exceptions for end-of-life situations both locally and nationally in Wave 1 of the pandemic, as reported in an environmental scan of ICU visitation policies.[14] Other factors potentially contributing to reduced in-person encounters include fear of contagion in relation to COVID-19 infection, and reduced access to hospital due to limitations in public or possibly personal transport as a result of the pandemic.[20]

To date, published quantitative data on frequency estimates of changes in in-person family presence or healthcare team-family communication in relation to end-of-life care in the pandemic is limited to a Swedish Register of Palliative Care (SRPC) study of hospitalized COVID-19 decedents (n=438), which reported family members were present at the time of death in only 24% of cases.[20] The study also reported that end-of-life discussions occurred with relatives in 87% of hospitalized decedents, but without a specific time reference and without distinguishing between in-person and telephone or other modality.[20] The SRPC data collection process relies on voluntary reporting and is designed to only record expected deaths, possibly resulting in missed cases, whereas the number of COVID-19 deaths (n=85) in our study is smaller but included all regional acute care hospital decedents in the study period. Consistent with published data, [4 20 24] our COVID+ve decedent cohort were on average relatively old, referred to hospital mostly from nursing home (long term care) facilities and mostly male. Despite the reduction in healthcare team-family in-person encounters, almost all patients (95%-97%) in the pandemic groups had a no CPR order in place at death, which compares favourably with published data on this metric,[17 18] and indicates that goals of care discussions likely occurred using modalities other than in-person communication.

Our study found that healthcare team-family telephone encounters increased markedly during the pandemic, particularly in relation to COVID+ve decedents. Virtual communication encounters occurred rarely in the pre-pandemic period, perhaps due to lesser need with the availability of preferred in-person encounters.

Virtual communications at end-of-life were adopted intra-pandemically, and were used by 42% of both decedent groups for family-patient encounters in this period, especially in COVID+ve decedents.

Compared to the pre-pandemic period, there were statistically significant changes in involvement of medical social work, physiotherapy and occupational therapy, with increases occurring in the COVID-ve group and decreases in the COVID+ve group. It is unclear whether these findings reflect greater intensity of discharge planning activity in the COVID -ve group, or greater availability of these personnel due to reduced involvement with the COVID+ve group. Intra-pandemically, the proportions of palliative care consultations and spiritual care involvement were largely maintained, with a non-statistically significant reduction of both in the COVID+ve group.

Study implications

Collectively, our findings have implications for patients and their families, and both the healthcare team and administrative policy.[15 25] For patients, in whom "the fear of dying alone is nearly universal",[26] reduced end-of-life contact with family and reduced interprofessional team input may compound their existing distress. Furthermore, patients with end-of-life delirium may be deprived of family reorientation efforts and the presence of a familiar face as a source of comfort.[27 28]

For family members of dying patients, reduced in-person contact with their loved one increases the risk of complicated grief.[12] It is unclear as to how much virtual communication might mitigate the risks associated with absence of in-person family contact, but clearly a modality worthy of further evaluation.[29-31] Although families appreciate the availability of virtual communication with their family member or the healthcare team,[28 31] their preference clearly remains to have in-person communication.[32 33] Our study's data will also be used in a prospective evaluation of grief in bereaved family members.

For the healthcare team, conducting in person end-of-life discussions is challenging even in the absence of a pandemic; in the presence of the pandemic, they may resort to alternative communication modalities, as they appeared to do in our study, albeit with some uncertainty as to whether the process, or quality associated with these modalities meet the desired outcomes that are associated with conventional in-person communication. There are many reports of moral distress in physicians and nurses during the pandemic; caring for patients dying

alone without any family present is cited as a major contributor to this.[34-37] For hospital administrative policy development, there is the ethical challenge of balancing the patient and family need for in-person contact at end-of-life against the measures to reduce infection risk with COVID-19,[13 38] in addition to legal considerations.[38]

Study strengths and limitations

Cohort groups were effectively matched, and there were no missing data in a decedent cohort that was representative of the regional source population in all acute care hospitals. We acknowledge that many of the early COVID-19 pandemic deaths occurred in nursing home or long-term care facilities, and our study findings may have limited generalizability in relation to such settings. Other limitations include the retrospective nature of the study, absence of a qualitative assessment of communication encounters, and the possibility of misclassification bias in data abstraction, which could have occurred despite rigorous training and data accuracy checks.

Conclusions

In hospitalized COVID-19 pandemic Wave 1 decedents, families' physical presence and in-person healthcare team-family communication encounters were markedly reduced at end-of-life; virtual modalities were adopted to a limited extent, more so in patient-family than healthcare team-family encounters, and telephone use was increased in healthcare team-family communications. Although allied health interprofessional team members had lesser involvement intra-pandemically in those dying of COVID-19 infection, spiritual care and palliative care involvement was maintained at just below pre-pandemic levels. Future studies are required to examine the implications of the pandemic-related communication changes for the patient, the family, and the healthcare team.

Acknowledgements

The authors are grateful to Dong Vo, Ottawa Methods Centre's Data Management Services and Ottawa Hospital Research Institute for the creation of an electronic study database, and to Dr Tim Ramsay, Scientific Director, Ottawa Methods Centre and Senior Scientist, Ottawa Hospital Research Institute for his statistical advice. We gratefully acknowledge the input of representatives from Bereaved Families of Ontario, Canadian Virtual Hospice and the Champlain Hospice Palliative Care Program.

Contributors

JD conceptualized the project and designed the study with assistance from PL, HP, LC, VG, RM, GW, AB, KW, JL, CW, DB, PE, ID, KB, CD, AI, SB, SI, PT, BV. The study site leads, HP, VG, LC, co-ordinated ethics applications along with PL, JL and DB. Data were abstracted by PL, HP, SRA, EB, LC, RM, GW, AB, KAH, KW, PE, ID, KB and CD. Data verification was coordinated by PL with the assistance of HP, SRA, EB, LC, RM, GW, AB, PE and KB. Statistical analyses were performed by PL and CW. All authors assisted with data interpretation. The original version of the manuscript was drafted by PL and critically reviewed by all authors. All authors approved the final manuscript as submitted.

Funding

This work has been funded in part by a grant from the University of Ottawa Faculty of Medicine COVID-19 Pandemic Response Funding Program, and in part by a contribution from Health Canada, Health Care Policy and Strategies Program. The views expressed herein do not necessarily represent the views of Health Canada nor the University of Ottawa.

Declaration of conflicting interests

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

References

1. Huang C, Wang Y, Li X, et al. Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China. *Lancet (London, England)* 2020;395(10223):497-506. doi: 10.1016/s0140-6736(20)30183-5 [published Online First: 2020/01/28]

2. World Health Organisation. WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020 2020 [Available from: https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020 accessed 27/12/2021 2021.

3. Docherty AB, Harrison EM, Green CA, et al. Features of 20 133 UK patients in hospital with covid-19 using the ISARIC WHO Clinical Characterisation Protocol: prospective observational cohort study. *BMJ (Clinical research ed)* 2020;369:m1985. doi: 10.1136/bmj.m1985 [published Online First: 2020/05/24]

4. Murthy S, Archambault PM, Atique A, et al. Characteristics and outcomes of patients with COVID-19 admitted to hospital and intensive care in the first phase of the pandemic in Canada: a national cohort study. *CMAJ open* 2021;9(1):E181-e88. doi: 10.9778/cmajo.20200250 [published Online First: 2021/03/11]

5. Petrilli CM, Jones SA, Yang J, et al. Factors associated with hospital admission and critical illness among 5279 people with coronavirus disease 2019 in New York City: prospective cohort study. *BMJ (Clinical research ed)* 2020;369:m1966. doi: 10.1136/bmj.m1966 [published Online First: 2020/05/24]

6. Radbruch L, De Lima L, Knaul F, et al. Redefining Palliative Care-A New Consensus-Based Definition. *Journal of Pain and Symptom Management* 2020;60(4):754-64. doi: 10.1016/j.jpainsymman.2020.04.027 [published Online First: 2020/05/11]

7. Selman LE, Brighton LJ, Sinclair S, et al. Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries. *Palliative Medicine* 2018;32(1):216-30. doi: 10.1177/0269216317734954 [published Online First: 2017/10/13]

8. World Health Organization. WHO Palliative Care 2002 [Available from: https://www.who.int/health-topics/palliative-care accessed 27/12/2021.

9. Hanna JR, Rapa E, Dalton LJ, et al. A qualitative study of bereaved relatives' end of life experiences during the COVID-19 pandemic. *Palliative Medicine* 2021;35(5):843-51. doi: 10.1177/02692163211004210 [published Online First: 2021/04/01]

10. Mayland CR, Hughes R, Lane S, et al. Are public health measures and individualised care compatible in the face of a pandemic? A national observational study of bereaved relatives' experiences during the COVID-19 pandemic. *Palliative Medicine* 2021;35(8):1480-91. doi: 10.1177/02692163211019885 [published Online First: 2021/06/01]

11. Schloesser K, Simon ST, Pauli B, et al. "Saying goodbye all alone with no close support was difficult"- Dying during the COVID-19 pandemic: an online survey among bereaved relatives about end-of-life care for patients with or without SARS-CoV2 infection. *BMC Health Services Research* 2021;21(1):998. doi: 10.1186/s12913-021-06987-z [published Online First: 2021/09/24]

12. Kentish-Barnes N, Chaize M, Seegers V, et al. Complicated grief after death of a relative in the intensive care unit. *The European Respiratory Journal* 2015;45(5):1341-52. doi: 10.1183/09031936.00160014 [published Online First: 2015/01/24]

13. Downar J, Kekewich M. Improving family access to dying patients during the COVID-19 pandemic. *The Lancet Respiratory Medicine* 2021;9(4):335-37. doi: 10.1016/s2213-2600(21)00025-4 [published Online First: 2021/01/16]

14. Fiest KM, Krewulak KD, Hiploylee C, et al. An environmental scan of visitation policies in Canadian intensive care units during the first wave of the COVID-19 pandemic. *Canadian Journal of Anaesthesia = Journal Canadien D'anesthesie* 2021;68(10):1474-84. doi: 10.1007/s12630-021-02049-4 [published Online First: 2021/07/02]

15. Moss SJ, Krewulak KD, Stelfox HT, et al. Restricted visitation policies in acute care settings during the COVID-19 pandemic: a scoping review. *Critical Care (London, England)* 2021;25(1):347. doi: 10.1186/s13054-021-03763-7 [published Online First: 2021/09/27]

16. Kentish-Barnes N, Cohen-Solal Z, Morin L, et al. Lived Experiences of Family Members of Patients With Severe COVID-19 Who Died in Intensive Care Units in France. *JAMA Netw Open* 2021;4(6):e2113355. doi: 10.1001/jamanetworkopen.2021.13355 [published Online First: 2021/06/22]

17. Connellan D, Diffley K, McCabe J, et al. Documentation of Do-Not-Attempt-Cardiopulmonary-Resuscitation orders amid the COVID-19 pandemic. *Age and Ageing* 2021;50(4):1048-51. doi: 10.1093/ageing/afab075 [published Online First: 2021/04/29]

18. Reidy J, Savageau JA, Sullivan K, et al. Assessing Goals-of-Care Documentation during the COVID-19 Patient Surge in an Academic Safety-Net Medical Center. *Journal of Palliative Medicine* 2021 doi: 10.1089/jpm.2021.0172 [published Online First: 2021/08/18]

19. Martinsson L, Bergström J, Hedman C, et al. Symptoms, symptom relief and support in COVID-19 patients dying in hospitals during the first pandemic wave. *BMC Palliative Care* 2021;20(1):102. doi: 10.1186/s12904-021-00785-4 [published Online First: 2021/07/03]

20. Strang P, Bergström J, Martinsson L, et al. Dying From COVID-19: Loneliness, End-of-Life Discussions, and Support for Patients and Their Families in Nursing Homes and Hospitals. A National Register Study. *Journal of Pain and Symptom Management* 2020;60(4):e2-e13. doi: 10.1016/j.jpainsymman.2020.07.020 [published Online First: 2020/07/30]

21. von Elm E, Altman DG, Egger M, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *PLoS Medicine* 2007;4(10):e296. doi: 10.1371/journal.pmed.0040296 [published Online First: 2007/10/19]

22. Government of Ontario. COVID-19 case numbers and spread [Available from: https://covid-19.ontario.ca/data/case-numbers-and-spread accessed 27/12/2021.

23. Piscitello GM, Fukushima CM, Saulitis AK, et al. Family Meetings in the Intensive Care Unit During the Coronavirus Disease 2019 Pandemic. *Am J Hosp Palliat Care* 2021;38(3):305-12. doi: 10.1177/1049909120973431 [published Online First: 2020/11/20]

24. Pastor-Barriuso R, Pérez-Gómez B, Hernán MA, et al. Infection fatality risk for SARS-CoV-2 in community dwelling population of Spain: nationwide seroepidemiological study. *BMJ (Clinical research ed)* 2020;371:m4509. doi: 10.1136/bmj.m4509 [published Online First: 2020/11/29]

25. Hugelius K, Harada N, Marutani M. Consequences of visiting restrictions during the COVID-19 pandemic: An integrative review. *International Journal of Nursing Studies* 2021;121:104000. doi: 10.1016/j.ijnurstu.2021.104000 [published Online First: 2021/07/10]

26. Wakam GK, Montgomery JR, Biesterveld BE, et al. Not Dying Alone - Modern Compassionate Care in the Covid-19 Pandemic. *The New England Journal of Medicine* 2020;382(24):e88. doi: 10.1056/NEJMp2007781 [published Online First: 2020/04/15]

27. Pun BT, Badenes R, Heras La Calle G, et al. Prevalence and risk factors for delirium in critically ill patients with COVID-19 (COVID-D): a multicentre cohort study. *The Lancet Respiratory Medicine* 2021;9(3):239-50. doi: 10.1016/s2213-2600(20)30552-x [published Online First: 2021/01/12]

28. Rose L, Yu L, Casey J, et al. Communication and Virtual Visiting for Families of Patients in Intensive Care during the COVID-19 Pandemic: A UK National Survey. *Annals of the American Thoracic Society* 2021;18(10):1685-92. doi: 10.1513/AnnalsATS.202012-1500OC [published Online First: 2021/02/23]

29. Bloomer MJ, Walshe C. Smiles behind the masks: A systematic review and narrative synthesis exploring how family members of seriously ill or dying patients are supported during infectious disease outbreaks. *Palliative Medicine* 2021;35(8):1452-67. doi: 10.1177/02692163211029515 [published Online First: 2021/08/19]

30. Selman LE, Chao D, Sowden R, et al. Bereavement Support on the Frontline of COVID-19: Recommendations for Hospital Clinicians. *Journal of Pain and Symptom Management* 2020;60(2):e81-e86. doi: 10.1016/j.jpainsymman.2020.04.024 [published Online First: 2020/05/08]

31. Cherniwchan HR. Harnessing New and Existing Virtual Platforms to Meet the Demand for Increased Inpatient Palliative Care Services During the COVID-19 Pandemic: A 5 Key Themes Literature Review of the Characteristics and Barriers of These Evolving Technologies. *Am J Hosp Palliat Care* 2021:10499091211036698. doi: 10.1177/10499091211036698 [published Online First: 2021/08/07]

32. Kennedy NR, Steinberg A, Arnold RM, et al. Perspectives on Telephone and Video Communication in the Intensive Care Unit during COVID-19. *Annals of the American Thoracic Society* 2021;18(5):838-47. doi: 10.1513/AnnalsATS.202006-729OC [published Online First: 2020/11/13]

33. Mercadante S, Adile C, Ferrera P, et al. Palliative Care in the Time of COVID-19. *Journal of Pain and Symptom Management* 2020;60(2):e79-e80. doi: 10.1016/j.jpainsymman.2020.04.025 [published Online First: 2020/05/08]

34. McMillan K, Wright DK, McPherson CJ, et al. Visitor Restrictions, Palliative Care, and Epistemic Agency: A Qualitative Study of Nurses' Relational Practice During the Coronavirus Pandemic. *Glob Qual Nurs Res* 2021;8:23333936211051702. doi: 10.1177/23333936211051702 [published Online First: 2021/11/12]

35. Villa M, Balice-Bourgois C, Tolotti A, et al. Ethical Conflict and Its Psychological Correlates among Hospital Nurses in the Pandemic: A Cross-Sectional Study within Swiss COVID-19 and Non-COVID-19 Wards. *Int J Environ Res Public Health* 2021;18(22) doi: 10.3390/ijerph182212012 [published Online First: 2021/11/28]

36. Anderson-Shaw LK, Zar FA. COVID-19, Moral Conflict, Distress, and Dying Alone. *Journal of Bioethical Inquiry* 2020;17(4):777-82. doi: 10.1007/s11673-020-10040-9 [published Online First: 2020/11/11]

37. Cook DJ, Takaoka A, Hoad N, et al. Clinician Perspectives on Caring for Dying Patients During the Pandemic : A Mixed-Methods Study. *Annals of Internal Medicine* 2021;174(4):493-500. doi: 10.7326/m20-6943 [published Online First: 2020/12/08]

38. Sudai M. Not Dying Alone: the Need to Democratize Hospital Visitation Policies During Covid-19. *Med Law Rev* 2021;29(4):613-38. doi: 10.1093/medlaw/fwab033 [published Online First: 2021/09/14]

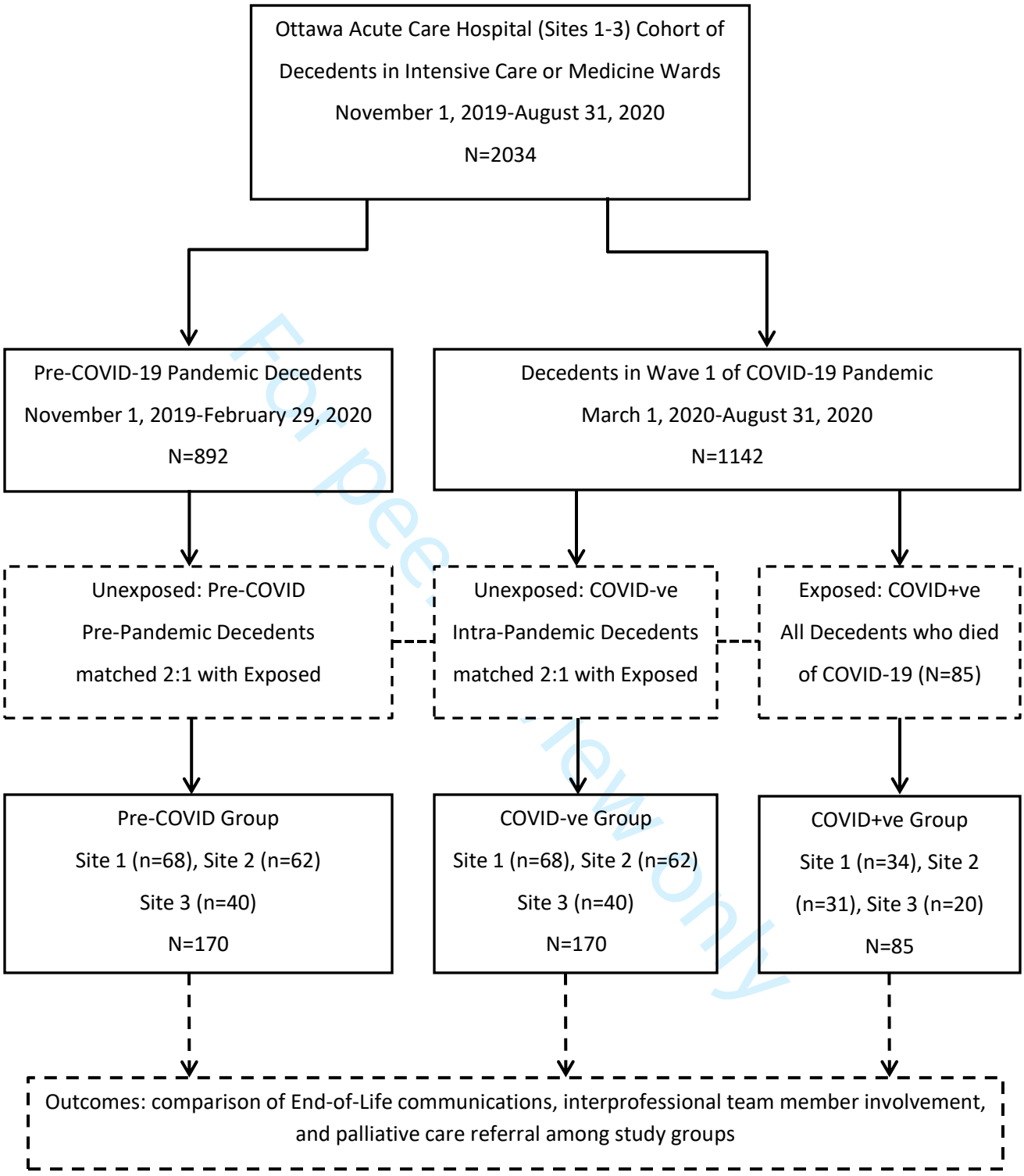
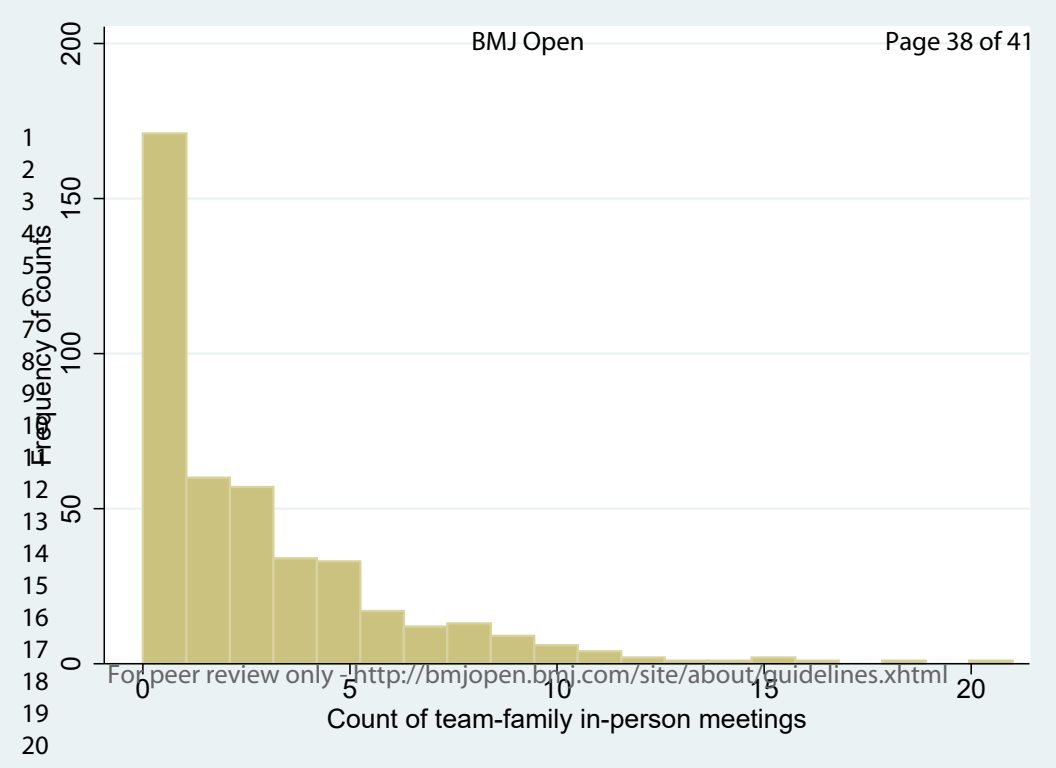
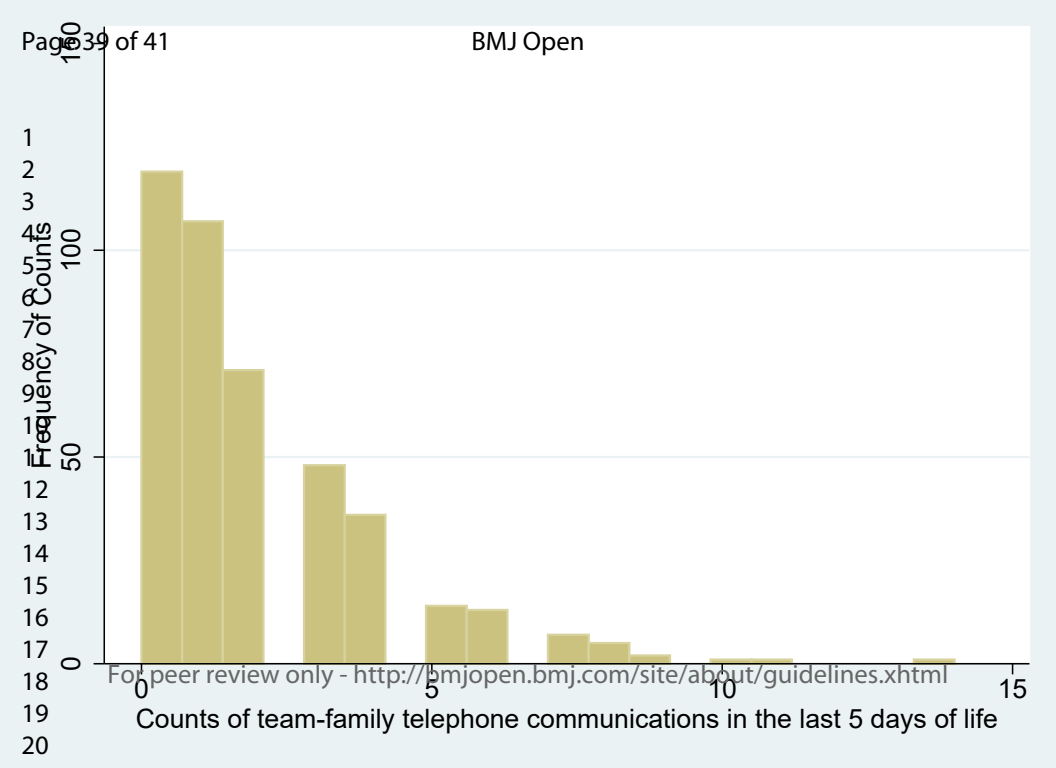


Figure 1 Study Flow Diagram of Study Group Derivation, Exposures, Matching and Outcomes





Appendix 3 Healthcare team-family virtual communication encounters in the last 5 days of life and variables examined in logistic regression analyses restricted to COVID-ve and COVID+ve groups

Virtual communication encounters and variables examined	Proportion of patients* (%)	Unadjusted OR (95% CI)		P value		Adjusted OR (95% CI)		P value
Occurrence: one or more	27/255 (10.6)							
Age of decedent$	…	0.99	(0.96-1.02)	0.340		0.995	(0.96-1.04)	0.808
Sex of decedent								
Female	9/105 (8.6)	1				1		
Male	18/150 (12.0)	1.46	(0.63-3.38)	0.383		1.35	(0.55-3.32)	0.516
Study group†								
COVID-ve	10/170 (5.9)	**1**				**1**		
COVID+ve	17/85 (20.0)	**4.00**	**(1.74-9.18)**	**0.001**		**3.68**	**(1.51-8.95)**	**0.004**
Hospital site								
Site 1	15/102 (14.71)	**1**				1		
Site 2	**5/93 (5.4)**	**0.33**	**(0.12-0.95)**	**0.039**		0.32	(0.10-1.02)	0.053
Site 3	7/60 (11.7)	0.77	(0.29-2.00)	0.586		0.79	(0.28-2.21)	0.649
Care service at death								
Medicine	**15/184 (8.2)**	**1**				1		
Intensive Care Unit	**12/71 (16.9)**	**2.29**	**(1.01-5.18)**	**0.046**		1.92	(0.69-5.37)	0.213
Admission duration$	…	0.997	(0.98-1.01)	0.697		0.997	(0.98-1.02)	0.747

Family present in-person								
Yes	15/175 (8.6)	1				1		
No	12/80 (15.0)	1.88	(0.84-4.23)	0.126		1.61	(0.63-4.10)	0.319

*Proportion of patients = proportion of total number for each categorical variable; OR = Odds Ratio;

$Treated as a continuous variable or covariate

†Pre-COVID group were excluded from the bivariable and multivariable analyses

STROBE Statement—Checklist of items that should be included in reports of ***cohort studies***

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	9-10
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	12
Objectives	3	State specific objectives, including any prespecified hypotheses	12-13
Methods			
Study design	4	Present key elements of study design early in the paper	13
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	13-14
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up (*b*) For matched studies, give matching criteria and number of exposed and unexposed	14
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	14-15
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	14
Bias	9	Describe any efforts to address potential sources of bias	15
Study size	10	Explain how the study size was arrived at	15
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	15-16
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding (*b*) Describe any methods used to examine subgroups and interactions (*c*) Explain how missing data were addressed (*d*) If applicable, explain how loss to follow-up was addressed (*e*) Describe any sensitivity analyses	16
Results			
12Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	16-17
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) Summarise follow-up time (eg, average and total amount)	16-18
Outcome data	15*	Report numbers of outcome events or summary measures over time	18-25

Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (*b*) Report category boundaries when continuous variables were categorized (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	18-25
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA
Discussion			
Key results	18	Summarise key results with reference to study objectives	25-28
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	28
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	25-28
Generalisability	21	Discuss the generalisability (external validity) of the study results	25-28
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	29

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at http://www.strobe-statement.org.

BMJ Open

Comparative end-of-life communication and support in hospitalized decedents before and during the COVID-19 pandemic: a retrospective regional cohort study in Ottawa, Canada

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-062937.R1
Article Type:	Original research
Date Submitted by the Author:	13-May-2022
Complete List of Authors:	Lawlor, Peter; Bruyere Research Institute, Palliative Care; University of Ottawa, Division of Palliative Care, Department of Medicine Parsons, Henrique; University of Ottawa, Division of Palliative Care, Department of Medicine; Ottawa Hospital, Medicine Adeli, Samantha ; University of Ottawa Besserer, Ella; University of Toronto Cohen, Leila; University of Ottawa, Division of Palliative Care, Department of Medicine; Queensway Carleton Hospital, Medicine Gratton, Valérie; University of Ottawa, Division of Palliative Care, Department of Medicine; Institut du Savoir Montfort, Medicine Murphy, Rebekah; University of Ottawa, Division of Palliative Care, Department of Medicine; Queensway Carleton Hospital, Medicine Warmels, Grace; University of Ottawa, Division of Palliative Care, Department of Medicine; Queensway Carleton Hospital, Medicine Bruni, Adrianna; University of Ottawa, Division of Palliative Care, Department of Medicine; Queensway Carleton Hospital, Medicine Kabir, Monisha; Bruyere Research Institute, Palliative Care Noel, Chelsea; University of Ottawa, Psychology; Bruyere Research Institute, Heidenger, Brandon; Bruyere Research Institute, Palliative Care Anderson, Koby; Bruyere Research Institute, Palliative Care Arsenault-Mehta, Kyle; University of Ottawa, Psychiatry Wooller, Krista; Ottawa Hospital; University of Ottawa Department of Medicine Lapenskie, Julie; Bruyère Research Institute; Ottawa Hospital Research Institute Webber, Colleen; Bruyere Research Institute, ; Ottawa Hospital Research Institute, Bedard, Daniel; Institut du Savoir Montfort, Enright, Paula ; Ottawa Hospital, Division of Palliative Care, Department of Medicine Desjardins, Isabelle; Ottawa Hospital General Campus, Medicine; University of Ottawa Department of Medicine Bhimji, Khadija; University of Ottawa, Division of Palliative Care, Department of Medicine; Queensway Carleton Hospital, Medicine Dyason, Claire; University of Ottawa, Division of Palliative Care, Department of Medicine; Ottawa Hospital Iyengar , Akshai ; University of Ottawa, Medicine; Queensway Carleton

	Hospital, Medicine Bush, Shirley H.; University of Ottawa, Division of Palliaitve Care, Department of Medicine; Bruyere Research Institute, Isenberg, Sarina; Bruyère Research Institute; University of Ottawa, Division of Palliative Care, Department of Medicine Tanuseputro, Peter; Ottawa Hospital Research Institute; Bruyère Research Institute Vanderspank-Wright, Brandi; University of Ottawa Faculty of Health Sciences, School of Nursing; Ottawa Hospital Research Institute, Downar, James; University of Ottawa, Divisions of Palliative Care and Critical Care, Department of Medicine; Bruyere Research Institute
Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Communication
Keywords:	COVID-19, GENERAL MEDICINE (see Internal Medicine), Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Adult intensive & critical care < INTENSIVE & CRITICAL CARE, Adult palliative care < PALLIATIVE CARE, GERIATRIC MEDICINE

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Comparative end-of-life communication and support in hospitalized decedents before and during the COVID-19 pandemic: a retrospective regional cohort study in Ottawa, Canada

Peter Lawlor MB FRCPI MMedSc

Senior Investigator, Bruyère Research Institute

Clinician Investigator, Ottawa Hospital Research Institute,

Professor, Division of Palliative Care, Dept of Medicine, University of Ottawa

plawlor@bruyere.org

ORCID ID: 0000-0001-7319-1395 [Corresponding Author]

Henrique Parsons MD MSc

Clinician Investigator, Ottawa Hospital Research Institute, Bruyère Research Institute

Associate Professor, Division of Palliative Care, Department of Medicine, University of Ottawa

hparsons@toh.ca

Samantha Rose Adeli RD

MS2, Class of 2024, Faculty of Medicine, University of Ottawa

sadel029@uottawa.ca

Ella Besserer

Physician Assistant Student Y2, The University of Toronto Class of 2022

ellabesserer@gmail.com

Leila Cohen MD

Palliative Care Physician, Department Medicine, The Ottawa Hospital

lecohen@toh.ca

Valérie Gratton MD

Palliative Care Physician, Montfort Hospital

Clinical Researcher, Institut du Savoir Montfort

Assistant Professor, Division of Palliative Care, Department of Medicine, University of Ottawa

valeriegratton@montfort.on.ca

Rebekah Murphy MD

Palliative Care Physician, Department Medicine, The Ottawa Hospital

RMurphy@bruyere.org

Grace Warmels BA MD CCFP(PC)

Palliative Care Physician, Department Medicine, The Ottawa Hospital

Clinician Investigator, Ottawa Hospital Research Institute; Lecturer, Division of Palliative Care, Department of Medicine, University of Ottawa

gwarmels@toh.ca

Adrianna Bruni MD

Palliative Care Physician, Department Medicine, The Ottawa Hospital

adbruni@toh.ca

Monisha Kabir

Research Associate, Bruyère Research Institute

mkabir@bruyere.org

Chelsea Noel

Research Coordinator, Bruyère Research Institute

chelseaannenoel@gmail.com

Brandon Heidinger

Research Coordinator, Bruyère Research Institute

bheidinger@bruyere.org

Koby Anderson

Research Assistant, Bruyère Research Institute

KAnderson@bruyere.org

Kyle Arsenault-Mehta MD

PGY4 Resident in Psychiatry, University of Ottawa

karse056@uottawa.ca

Krista Wooller MD

Physician, Department of Medicine, The Ottawa Hospital

Assistant Professor, University of Ottawa

krwooller@toh.ca

Julie Lapenskie MScAH

Research Associate and Manager, Ottawa Hospital Research Institute and Bruyère Research Institute

JLapenskie@bruyere.org

Colleen Webber PhD

Senior Research Associate, The Ottawa Hospital Research Institute

cowebber@ohri.ca

Daniel Bédard MSc

Research Associate, Institut du Savoir Montfort

danielbedard@montfort.on.ca

Paula Enright MD

Palliative Care Physician, Department of Medicine, The Ottawa Hospital

Assistant Professor, Division of Palliative Care, Department of Medicine, University of Ottawa

penright@toh.ca

Isabelle Desjardins MD

Clinician Educator, Department of Medicine, University of Ottawa

idesjardins@toh.ca

Khadija Bhimji MSc MD FRCPC

Palliative Care Physician, Queensway Carleton Hospital

Assistant Professor, Division of Palliative Care, Department of Medicine, University of Ottawa

KBhimji@toh.ca

Claire Dyason MD

Palliative Care Physician, Department of Medicine, Queensway Carleton Hospital

Lecturer, Division of Palliative Care, Dept of Medicine, University of Ottawa

cdyason@toh.ca

Akshai Iyengar MSc MD FRCPC

Medical Director, Department of Critical Care Medicine, Queensway Carleton Hospital

Assistant Professor, University of Ottawa

aiyengar@qch.on.ca

Shirley H Bush MBBS DRCOG DCH MRCGP PgDip Pall Med FAChPM

Clinician Investigator, Ottawa Hospital Research Institute and Bruyère Research Institute

Associate Professor, Division of Palliative Care, Dept of Medicine, University of Ottawa sbush@bruyere.org

ORCID ID: 0000-0001-8907-1283

Sarina Isenberg MA PhD

Bruyère Chair in Mixed Methods Palliative Care Research, Bruyère Research Institute

Assistant Professor, Division of Palliative Care, Department of Medicine, University of Ottawa

Assistant Professor, Department of Family and Community Medicine, University of Toronto

sisenberg@bruyere.org

ORCID ID: 0000-0001-6059-5366

Peter Tanuseputro MD

Scientist, Clinical Epidemiology Program, Ottawa Hospital Research Institute

Investigator, Bruyère Research Institute, Assistant Professor, Division of Palliative Care, Dept of Medicine, University of Ottawa

ptanuseputro@toh.ca

Brandi Vanderspank-Wright PhD RN CNCC(C)

Associate Professor, Faculty of Health Sciences, School of Nursing, University of Ottawa

Affiliate Investigator, Ottawa Hospital Research Institute

bvanders@uottawa.ca

ORCID ID: 0000-0002-1908-8212

James Downar MDCM MHSc

Professor, Head of the Division of Palliative Care, Department of Medicine, University of Ottawa

Department of Palliative Care, Élisabeth Bruyère Hospital

jdownar@toh.ca

Correspondence to:

Dr Peter G Lawlor,

Dept of Palliative Care,

Bruyère Continuing Care,

43 Bruyère Street,

Ottawa,

Ontario

Canada K1N 5C8

Email: plawlor@bruyere.org

Tel: +16135626262

Fax: +16135626371

ABSTRACT

Objective

To compare end-of-life in-person family presence, patient-family communication and healthcare team-family communication encounters in hospitalized decedents before and during the COVID-19 pandemic.

Design

In a regional multicentre retrospective cohort study, electronic health record data were abstracted for a pre-pandemic group (Pre-COVID) and two intra-pandemic (March-August 2020, Wave 1) groups, one COVID-19-free (COVID-ve) and one with COVID-19 infection (COVID+ve). Pre-COVID and COVID-ve groups were matched 2:1 (age, sex and care service) with the COVID+ve group.

Setting

One quaternary and two tertiary adult, acute care hospitals in Ottawa, Canada.

Participants

Decedents (N=425): COVID+ve (n=85), COVID-ve (n=170) and Pre-COVID (n=170).

Main outcome measures

End-of-life (last 48 hours) in-person family presence and virtual (video) patient-family communication, and end-of-life (last 5 days) virtual team-family communication encounter occurrences were examined using logistic regression with odds ratios (ORs) and 95% confidence intervals (CIs). End-of-life (last 5 days) rates of in-person and telephone team-family communication encounters were examined using mixed-effects negative binomial models with Incidence rate ratios (IRRs) and 95% CIs.

Results

End-of-life in-person family presence decreased progressively across Pre-COVID (90.6%), COVID-ve (79.4%) and COVID+ve (47.1%) groups: adjusted ORs=0.38 (0.2-0.73) and 0.09 (0.04-0.17) for COVID-ve and COVID+ve groups, respectively. COVID-ve and COVID+ve groups had reduced in-person but increased telephone team-family

communication encounters: IRRs=0.76 (0.64-0.9) and 0.61 (0.47-0.79) for in-person, and IRRs=2.6 (2.1-3.3) and 4.8 (3.7-6.1) for telephone communications, respectively. Virtual team-family communication encounters occurred in 17/85 (20%) and 10/170 (5.9%) of the COVID+ve and COVID-ve groups, respectively: adjusted OR=3.68 (1.51-8.95).

Conclusions

In hospitalized COVID-19 pandemic Wave 1 decedents, in-person family presence and in-person team-family communication encounters decreased at end-of-life, particularly in the COVID+ve group; virtual modalities were adopted for communication, and telephone use increased in team-family communication encounters. The implications of these communication changes for the patient, family, and healthcare team warrant further study.

Abstract: 297 words

Main manuscript: 3,196 words

Tables: 5

Figures: 1

Appendices: 3

Keywords: COVID-19, pandemic, end-of-life communication, palliative care, critical care, supportive care, interprofessional care, patient-provider communication

Strengths and limitations of this study

- There were no missing data in a decedent cohort that was representative of the source population in all adult acute care hospitals in a large urban region.
- Although cohort groups were effectively matched on the basis of age, sex and care service, other baseline differences could have existed between the groups.
- In data abstraction, we cannot exclude the possibility of misclassification bias, which could have occurred despite rigorous training and data accuracy checks; the absence of abstractor blinding in relation to the study hypothesis was also a potential source of bias.
- The retrospective nature of the study and the absence of a qualitative assessment to assess the depth and more detailed content of communication during encounters are acknowledged limitations.
- The generalizability of our study findings is largely limited to end-of-life care for hospitalized decedents, whereas many of the COVI-19 pandemic related deaths occurred in nursing homes.

INTRODUCTION

Coronavirus disease 2019 (COVID-19) emerged in late 2019 and became a global pandemic within three months.[1 2] COVID-19 infection is associated with high rates of hospitalization, intensive care unit (ICU) admission, and increased mortality, particularly in older people, the frail and those with chronic medical conditions.[3-5] These metrics underscore the need to integrate a palliative approach that includes shared decision-making, sensitive goals of care discussions respecting patient and family preferences, and meeting the psychosocial and spiritual needs of patients and their families facing a life-threatening illness.[6-8] Communication involving the patient, family and healthcare team triad, particularly in-person, is an integrative component of a proactive palliative approach in non-pandemic times,[8] and highly valued by family members in their subsequent bereavement.[9-11] Moreover, in-person communication is a fundamental human need and inability to say goodbye prior to death of a loved one has been identified as a predictor of complicated grief in bereavement.[12]

The pandemic associated increase in end-of-life care communicative needs has been further compounded by the introduction of strict infection control measures, including visitor restriction and patient isolation policies for hospitalized patients.[13-15] Although mandated from a public health perspective, these measures pose obstacles to end-of-life communication.[11 13 16]

Studies specifically examining end-of-life communication issues during the COVID-19 pandemic have, to date, been mostly qualitative and relatively limited in quantifying these phenomena, or were restricted in focus, such as resuscitation status,[17 18] or reliant on voluntary reporting.[19 20] To address these gaps, we retrospectively examined end-of-life care in relation to the COVID-19 pandemic in adult acute care hospitals in an urban region. We hypothesized that the pandemic-related visitor and isolation restrictions imposed in these hospitals were associated with a reduced number of in-person, face-to-face, healthcare team-family and family-patient communications, and an increase in alternative communication modalities, such as tele- or virtual (video) conferencing. The primary study objective was to examine the impact of COVID-19 status on patient-family and healthcare team-family communication encounters during end-of-life care. We compared those dying pre-pandemically versus those dying during Wave 1 of the pandemic, due to recorded COVID-19 infection itself versus

other causes, without COVID-19 infection. Comparative allied health involvement, palliative medicine consultation and resuscitation order status were examined as additional objectives.

Methods

Study design

We conducted a multicentre retrospective matched cohort study of decedents' documented end-of-life care in adult acute tertiary or quaternary care hospitals. The study is reported in accordance with the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) criteria.[21]

Setting

The source population consisted of inpatients in Ottawa (population 1.4 million), Canada, who died in the city's three adult acute care hospital sites between November 1, 2019 and August 31, 2020. Site 1, The Ottawa Hospital is a quaternary acute care hospital with 1271 inpatient beds. Site 2, The Hôpital Montfort is a tertiary acute care francophone academic hospital with 289 inpatient beds. Site 3, The Queensway-Carleton Hospital is a tertiary acute care hospital with 264 inpatient beds. All sites used established electronic health records (EHR) systems, Epic (Epic Systems Corporation) at Site 1 and MEDITECH (Medical Information Technology, Inc.) at Sites 2 and 3, for documentation of patient care and encounters with family.

Approximately 2487 people were diagnosed with COVID-19 in Ottawa between March 1 and August 31, 2020, of whom 266 died, including 85 in acute care hospitals.[22] Public health measures and restrictions were applied throughout Ontario, including in acute care hospitals, in early March 2020, and remained largely in place until the end of the study period.

The study's key exposures related to COVID-19 infection status during decedents' hospital admission and the timing of the admission in relation to the pandemic. Based on these exposures, 3 study groups were designated: a Pre-COVID group who died prior to the COVID-19 pandemic (deaths occurring between November 1st 2019 and February 29th 2020); and 2 groups whose deaths occurred within the initial, Wave 1 of the pandemic

(March 1st 2020 to August 31st 2020), one without any record of COVID-19 during their hospital admission and the other who died of COVID-19 infection, designated COVID-ve and COVID+ve, respectively.

Participants

Adult (≥ 18 years old) decedents were eligible for inclusion if they died in ICU or under the care of a medical service in the study period. Emergency department decedents and those primarily under surgical care were excluded. The index study group was COVID+ve; all (n=85) of these decedents were included. The Pre-COVID (n=170) and COVID-ve (n=170) group members were matched 2:1 with the COVID+ve members from each site on the basis of age (± 5 years), sex and care service (Medicine or ICU) at the time of death.

Data sources/measurement

Using a common electronic study database across sites, anonymized EHR data, including study variables were abstracted by teams of internal/palliative medicine physicians and two research assistants. All abstractors received training regarding abstraction requirements. Of all patient records, 154 (35%) underwent duplicate abstraction to confirm accuracy of details.

Variables

Study group designation was based on EHR documentation of COVID-19 infection status, date of death and death certification. Demographic variables included age, sex, admission referral source, acute care site, care service at death, and admission duration (days). The association of these variables was examined in relation to the occurrence of patient-family and healthcare team-family communicative encounters. Admission duration was included as a potential confounder, as decedents were not matched on this criterion. Clustering in association with either location or actual presence of family in the last 48 hours was anticipated and adjusted for in multivariable analyses.

Documented family-patient communicative interactions involving physical presence and virtual presence in the last 48 hours of life, were each recorded as outcomes and each treated as binary (Yes/No) variables. The outcomes of documented healthcare team (physician, nursing and allied health)-family interactive encounters

(physical presence, telephone conversations, and virtual presence) in the last 5 days of life, were each recorded as a total count, based on individual note entries in the EHR. As an implicit measure of quality end-of-life care across our study sites, and for legal reasons, any family-healthcare team communication, irrespective of modality, that involves patient care decisions, would be expected to be recorded in the HER. In the absence of family, the decedent's substitute decision maker was included within the category of family. The involvement of allied health professionals, palliative medicine consultation and the documented presence of a no cardiopulmonary resuscitation (CPR) order were recorded as binary variables and represented additional indices of end-of-life communication and support.

Patient and public involvement

The retrospectively acquired decedent data in this study is part of an overall project that involves an ongoing prospective evaluation of grief in decedents' bereaved family members. Although there was no direct patient or public involvement in the retrospective component of the project, we engaged with three different knowledge user organizations (Bereaved Families of Ontario, Canadian Virtual Hospice and Champlain Hospice Palliative Care Program), whose representatives collaborated with the study planning team and were co-applicants in funding applications for the overall project.

Ethics

The Research Ethics Boards (REBs) of each hospital approved the study: Ottawa Health Science Network-REB (20200653-01H, December 18th 2020); Montfort REB (20-21-10-032, December 2nd 2020) and Queensway Carleton Hospital REB (20-06, December 1st 2020).

Bias

Data abstractors were not blinded as to the study objectives and consequently misclassification bias cannot be ruled out. Matching variables were included a priori in multivariable models of the main outcomes.

Study size

The sample size was determined by the inclusion of all Wave 1 deaths due to COVID-19 (COVID+ve, n=85) and the subsequent 2:1 matching to generate the other two study groups.

Quantitative variables

Healthcare team-family interactions in the last 5 days of life were treated as count data and summarized as median (interquartile, Q1-Q3 range); other continuous variables were expressed as mean ± standard deviation (SD) unless otherwise indicated.

Statistical methods

Demographic characteristics, allied health involvement, palliative medicine consultation and resuscitation order status were compared among study groups, using a chi-square test for categorical variables, and an ANOVA or Kruskal-Wallis test for continuous variables, as appropriate. The presence of family was reported using unadjusted and adjusted multivariable logistic regression, reporting odds ratios (ORs) and corresponding 95% confidence intervals (CIs). The comparison of virtual patient-family encounters was restricted to the intra-pandemic groups, as these encounters were rarely documented pre-pandemically. The count distribution of healthcare team-family in-person **(Appendix 1)** and telephone interactions **(Appendix 2)** were zero inflated and overdispersed, with potential clustering both by site and family presence in the last 48 hours of life. Consequently, mixed effects negative binomial models were used, including site and family presence in the last 48 hours as random effects and reporting incidence rate ratios (IRRs) with 95% CIs for in-person and telephone interactions among the groups. Due to absence of virtual healthcare team-family encounters pre-pandemically, and their infrequent occurrence in the intra-pandemic groups, the initial total counts underwent binary transformation to reflect occurrence or non-occurrence, and group comparison was restricted to the intra-pandemic groups. Stata (StataCorp. 2015. *Stata Statistical Software: Release 14*. College Station, TX: StataCorp LP.) was used for statistical analysis, and statistical significance was set at $p < 0.05$.

Results

Study sample derivation and demographic data

The final study sample of 425 decedents consisted of the Pre-COVID (n=170), COVID-ve (n=170) and COVID+ve (n=85) groups **(Figure 1)**.

<<<< Insert Figure 1 here>>>>

Comparison of demographic data revealed no statistically significant difference among the study groups regarding the matching criteria **(Table 1).**

Table 1. Demographic characteristics among study groups designated according to COVID-19 status

Demographic characteristics	**Time periods and designated study groups**			**P values**
	Nov 2019-Feb 2020	**Mar 2020 – Aug 2020**		
	Pre-COVID Group N=170 (%)*	**COVID-ve Group N=170 (%)***	**COVID+ve Group N=85 (%)***	
Age				
Years, mean ± SD	79.5 ± 12.3	79.2 ± 12.3	78.9 ± 12.2	0.942
Sex				
Male	100 (58.8)	100 (58.8)	50 (58.8)	1.0
Admission referral source				
Home	99 (58.2)	109 (64.1)	31 (36.5)	**<0.001**
Retirement home	36 (21.2)	34 (20.0)	11 (11.8)	

Nursing home / long term care	22 (12.9)	8 (4.7)	43 (50.6)	
Complex continuing care	2 (1.2)	2 (1.2)	0 (0.0)	
Other	11 (6.5)	17 (10.0)	1 (1.2)	
Care service at death				
Medicine service/unit	118 (69.4)	122 (71.7)	62 (72.9)	0.814
Intensive Care Unit	52 (30.6)	48 (28.2)	23 (27.1)	
Admission duration				
Days, median [Q1-Q3]	6 (2-15)	9 (4-21)	6 (4-13)	0.062
Documented No CPR† order				
Present	160 (94.1)	161 (94.7)	82 (96.5)	0.724
Median days (Q1-Q3) pre-death if order present	3 (1-10)	5 (1-16)	5 (3-11)	0.184

* Column numbers refer to number of persons (%) in respective study groups unless stated otherwise.

†CPR=cardiopulmonary resuscitation.

The overall mean age was 79.3 ± 12.2 and the majority (58.8%) were male. Admission referrals from nursing homes were higher in the COVID+ve (50.6%) group compared to Pre-COVID (12.9%) or COVID-ve (4.7%) groups ($p<0.001$).

Family-patient communication encounters

In the last 48 hours of life, family member presence decreased progressively across the Pre-COVID (90.6%), COVID-ve (79.4%) and COVID+ve (47.1%) groups **(Table 2)**.

Table 2. In-person family presence in the last 48 hours of life and variables examined in logistic regression analyses

Variables examined	Proportion of patients* (%)	Unadjusted OR (95% CI)		P value		Adjusted OR (95% CI)		P value
In-person family presence	329/425 (77.4)							
Age of decedent†	…	0.997	(0.98-1.02)	0.774		0.99	(0.97-1.02)	0.608
Sex of decedent								
Female	139/175 (79.4)	1				1		
Male	190/250 (76.0)	0.82	(0.51-1.31)	0.406		0.75	(0.44-1.26)	0.272
Study group								
Pre-COVID	154/170 (90.6)	**1**				**1**		
COVID-ve	**135/170 (79.4)**	**0.40**	**(0.21-0.76)**	**0.005**		**0.38**	**(0.199-0.73)**	**0.003**
COVID+ve	**40/85 (47.1)**	**0.09**	**(0.05-0.18)**	**<0.001**		**0.09**	**(0.04-0.17)**	**<0.001**
Hospital site								
Site 1	138/170 (81.2)	**1**				**1**		
Site 2	**108/155 (69.7)**	**0.53**	**(0.32-0.89)**	**0.017**		**0.46**	**(0.26-0.84)**	**0.011**

Site 3	83/100 (83.0)	1.13	(0.59-2.17)	0.707		1.15	(0.56-2.34)	0.701
Care service at death								
Medicine	231/302 (76.5)	1				1		
Intensive Care Unit	98/123 (79.7)	1.21	(0.72-2.01)	0.477		0.92	(0.47-1.79)	0.801
Admission duration†	…	1.004	(0.99-1.01)	0.411		1.004	(0.99-1.02)	0.428

*Proportion of patients = proportion of total number for each categorical variable. OR = Odds Ratio.

†Treated as a continuous variable or covariate.

The unadjusted OR for family physical presence in the last 48 hours of life was 0.40 (0.21-0.76) and 0.09 (0.05-0.18) for the COVID-ve (p=0.005) and COVID+ve (p<0.001) groups, respectively, and 0.53 (0.32-0.89) for Site 2 (p=0.017). These findings were maintained with marginal differences in the multivariable model.

In the Pre-COVID group, only two virtual patient-family encounters were documented in the last 48 hours of life, compared to occurrence rates of 31.8% and 10% in the COVID-ve and COVID+ve groups, respectively. In a multivariable model restricted to the intra-pandemic decedents (n=255), the adjusted OR for the occurrence of a virtual encounter was 3.45 (1.67-7.15) and 2.14 (1.01-4.53) for the COVID+ve group (p=0.001) and for absence of a family member in the last 48 hour of life (p=0.048), respectively **(Table 3).**

Table 3. Virtual family presence in the last 48 hours of life and variables examined in logistic regression analyses

Variables examined	**Proportion of patients* (%)**	**Unadjusted OR (95% CI)**	**P value**		**Adjusted OR (95% CI)**	**P value**

Virtual family presence§	44/255 (17.3)							
Age of decedent†	…	1.01	(0.98-1.04)	0.402		1.02	(0.98-1.05)	0.334
Sex of decedent								
Female	19/105 (18.1)	1				1		
Male	25/150 (16.7)	0.91	(0.47-1.75)	0.766		0.88	(0.44-1.80)	0.734
Study group								
COVID-ve	17/170 (10.0)	**1**				**1**		
COVID+ve	27/85 (31.8)	**4.19**	**(2.13-8.25)**	**<0.001**		**3.45**	**(1.67-7.15)**	**0.001**
Hospital site								
Site 1	21/102 (20.6)	1				1		
Site 2	16/93 (17.2)	0.80	(0.39-1.65)	0.548		0.75	(0.33-1.70)	0.486
Site 3	7/60 (11.7)	0.51	(0.20-1.28)	0.152		0.55	(0.21-1.47)	0.235
Care service at death								
Medicine	31/184 (16.9)	1				1		
Intensive Care Unit	13/71 (18.3)	1.11	(0.54-2.26)	0.782		1.44	(0.58-3.53)	0.424
Admission duration†	…	0.997	(0.98-1.01)	0.600		1.001	(0.99-1.01)	0.855
Family present in-person in last 48 hours of life								

Yes	**21/175 (12.0)**	**1**				**1**		
No	**23/80 (28.8)**	**2.96**	**(1.52-5.75)**	**0.001**		**2.14**	**(1.007-4.53)**	**0.048**

*Proportion of patients = proportion of total number for each categorical variable. OR = Odds Ratio.

†Treated as a continuous variable or covariate.

§ Pre-COVID group (n=170) were excluded from the bivariable analyses and the multivariable model.

Healthcare team-family communication encounters

In the last 5 days of life, there was a 15% reduction in physical or in-person healthcare team communication encounters in male decedents compared to females, with IRR=0.85 (0.72-0.99), p=0.041 **(Table 4).**

Table 4. Number of healthcare team-family communication encounters in the last 5 days of life in mixed effects negative binomial models (A, In-person and B, telephone)*

Models and variables examined	Count†	Incidence Rate Ratio (95% CI)		P value
A. In-person encounter	2 (1-4)			
Age of decedent§	…	0.997	(0.99-1.004)	0.396
Sex of decedent (female)	2 (1-5)	1		
Sex of decedent (male)	2 (1-4)	**0.85**	**(0.72-0.99)**	**0.041**
Study group: exposure status				
Pre-COVID	3 (2-5)	**1**		
COVID-ve	2 (1-4)	**0.76**	**(0.64-0.90)**	**0.001**
COVID+ve	0 (0-2)	**0.61**	**(0.47-0.79)**	**<0.001**

Care service at death				
Medicine service	2 (0-5)	**1**		
Intensive Care Unit	2 (1-3)	**0.68**	**(0.55-0.84)**	**<0.001**
Days in hospital[§]	…	1.003	(0.999-1.006)	0.411
B. Telephone communications	1 (0-3)			
Age of decedent[§]	…	1.005	(0.996-1.01)	0.283
Sex of decedent (female)	1 (0-3)	1		
Sex of decedent (male)	1 (0-3)	1.002	(0.84-1.19)	0.984
Study group: exposure status				
Pre-COVID	1 (0-1)	1		
COVID-ve	2 (1-3)	**2.60**	**(2.09-3.25)**	**<0.001**
COVID+ve	4 (2-5)	**4.77**	**(3.72-6.12)**	**<0.001**
Care service at death				
Medicine	1 (0-3)	1		
Intensive Care Unit	1 (0-3)	1.16	(0.93-1.43)	0.189
Days in hospital[§]	…	0.998	(0.99-1.001)	0.203

*****Hospital site and family's physical presence in the last 48 hours of life were both included as random effects in both models.

†Counts for categorical variables, median (Q1-Q3).

[$]Treated as a continuous covariate in models.

There was an approximate 24% and 39% reduction in the incidence rate of these communications in the COVID-ve and COVID+ve groups, with IRRs of 0.76 (0.64-0.90) and 0.61 (0.47-0.79), p=0.001 and p<0.001, respectively. Compared to a medicine ward, death in ICU was associated with a 32% reduction in the incidence rate of in-person communications; IRR=0.68 (0.55-0.84), p<0.001.

In the model examining telephone communications between the healthcare team and family members in the last 5 days of life, there was a relative increase in the incidence rate of these communications in the COVID-ve and particularly in the COVID+ve groups, with IRRs of 2.6 (2.09-3.25) and 4.77 (3.72-6.12), p<0.001 for both, respectively.

Virtual healthcare team-family communication encounters occurred in 17 (20%) of the COVID+ve and 10 (5.9%) of COVID-ve decedents (p=0.001). Both COVID+ve status and death in the ICU were associated with an increased occurrence of virtual communication encounters, with unadjusted ORs of 4.0 (1.74-9.18) and 2.29 (1.01-5.18), p=0.001 and p=0.046, respectively **(Appendix 3).** Hospital Site 2 was associated with an unadjusted OR of 0.33 (0.12-0.95), p=0.039, for virtual communication encounters, compared to Hospital Site 1. However, only COVID+ve status had an independent association with virtual communications in a multivariable model, with an adjusted OR of 3.68 (1.51-8.95), p=0.004.

Interprofessional supportive care team involvement

Relative to the Pre-COVID group, with proportions of 41.2%, 45.9% and 30.4% for the respective involvement of physiotherapy, medical social work and occupational therapy during admission, the COVID-ve group had greater involvement (50.6%, 58.2% and 42.9%, respectively), whereas the COVID+ve group had lesser involvement of these disciplines with rates of 22.4%, 30.6% and 12.9%, respectively, p<0.001 for all **(Table 5).**

Table 5. Comparison of interprofessional team member involvement among study groups

Interprofessional team	**Time periods and designated groups**	**P value**

members	Nov 2019-Aug 2020	Nov 2019-Feb 2020	March 2020-August 2020		
	All Groups N=425 (%)*	Pre-COVID N=170 (%)*	COVID-ve N=170 (%)*	COVID+ve N=85 (%)*	
Physiotherapy	**175 (41.2)**	**70 (41.2)**	**86 (50.6)**	**19 (22.4)**	**<0.001**
Medical social worker	**195 (45.9)**	**70 (41.2)**	**99 (58.2)**	**26 (30.6)**	**<0.001**
Spiritual care	105 (24.7)	49 (28.8)	42 (24.7)	14 (16.5)	0.098
Occupational therapy	**129 (30.4)**	**45 (26.5)**	**73 (42.9)**	**11 (12.9)**	**<0.001**
Palliative care					
Consult requested	167 (39.3)	70 (41.2)	71 (41.8)	26 (30.6)	0.184
Consult completed	159 (37.4)	67 (39.4)	67 (39.4)	25 (29.4)	0.234
Days from consult completion to death (median, Q1-Q3)	3 (1-7)	4 (1-9)	3 (1-6)	3 (2-12)	0.577

*Column numbers refer to number of persons (%) within respective groups unless stated otherwise.

There were no statistically significant study group differences with respect to spiritual care or palliative care involvement, though the proportion with spiritual care involvement decreased from 28.8% in the Pre-COVID group to 12.9% in the COVID+ve group (p=0.098).

Discussion

Study findings and putative explanations

Our study found reduced physical presence of family at end-of-life for pandemic decedents, particularly in those dying with COVID-19 infection, with a reduction of almost 50% when compared to matched pre-pandemic controls. Although we adjusted for family presence at end-of-life, we found a reduced incidence rate of in-person healthcare team-family meetings in the last 5 days of life, most notably in the COVID+ve group, but also in male decedents and those dying in ICU, when compared to matched pre-pandemic controls. It is unclear if the matching process contributed to this finding in male decedents, whereas reduced in-person healthcare team-family encounters have previously been reported in ICU during the COVID-19 pandemic.[23]

The reductions in both types of in-person encounters in our study occurred in the context of pandemic-related patient isolation policies and visitor restrictions. Although visitor restrictions were introduced, there were efforts to make exceptions for end-of-life situations both locally and nationally in Wave 1 of the pandemic, as reported in an environmental scan of ICU visitation policies.[14] Other factors potentially contributing to reduced in-person encounters include fear of contagion in relation to COVID-19 infection, and reduced access to hospital due to limitations in public or possibly personal transport as a result of the pandemic.[20] Although site difference in access policy might be considered as an explanation for lesser family presence in the last 48 hours of life at Site 2, we found no evidence of such difference, and the cause of this finding is unclear.

To date, published quantitative data on frequency estimates of changes in in-person family presence or healthcare team-family communication in relation to end-of-life care in the pandemic is limited to a Swedish Register of Palliative Care (SRPC) study of hospitalized COVID-19 decedents (n=438), which reported family members were present at the time of death in only 24% of cases.[20] The study also reported that end-of-life discussions occurred with relatives in 87% of hospitalized decedents, but without a specific time reference and without distinguishing between in-person and telephone or other modality.[20] The SRPC data collection process relies on voluntary reporting and is designed to only record expected deaths, possibly resulting in missed cases, whereas the number of COVID-19 deaths (n=85) in our study is smaller but included all regional acute care hospital decedents in the study period. Consistent with published data, [4 20 24] our COVID+ve decedent cohort were on average relatively old, referred to hospital mostly from nursing home (long term care) facilities and mostly male. Despite the reduction in healthcare team-family in-person encounters, almost all patients (95%-97%) in the

pandemic groups had a no CPR order in place at death, which compares favourably with published data on this metric,[17 18] and indicates that goals of care discussions likely occurred using modalities other than in-person communication.

Our study found that healthcare team-family telephone encounters increased markedly during the pandemic, particularly in relation to COVID+ve decedents. Virtual communication encounters occurred rarely in the pre-pandemic period, perhaps due to lesser need with the availability of preferred in-person encounters. Virtual communications at end-of-life were adopted intra-pandemically and were used by 42% of both decedent groups for family-patient encounters in this period, especially in COVID+ve decedents.

Compared to the pre-pandemic period, there were statistically significant changes in involvement of medical social work, physiotherapy and occupational therapy, with increases occurring in the COVID-ve group and decreases in the COVID+ve group. It is unclear whether these findings reflect greater intensity of discharge planning activity in the COVID -ve group, or greater availability of these personnel due to reduced involvement with the COVID+ve group. Intra-pandemically, the proportions of palliative care consultations and spiritual care involvement were largely maintained, with a non-statistically significant reduction of both in the COVID+ve group.

Study implications

Collectively, our findings have implications for patients and their families, and both the healthcare team and administrative policy.[15 25] For patients, in whom "the fear of dying alone is nearly universal",[26] reduced end-of-life contact with family and reduced interprofessional team input may compound their existing distress. Furthermore, patients with end-of-life delirium may be deprived of family reorientation efforts and the presence of a familiar face as a source of comfort.[27 28]

For family members of dying patients, reduced in-person contact with their loved one increases the risk of complicated grief.[12] It is unclear as to how much virtual communication might mitigate the risks associated with absence of in-person family contact, but clearly a modality worthy of further evaluation.[29-31] Although families appreciate the availability of virtual communication with their family member or the healthcare team,[28 31] their

preference clearly remains to have in-person communication.[32 33] Our study's data will also be used in a prospective evaluation of grief in bereaved family members.

For the healthcare team, conducting in person end-of-life discussions is challenging even in the absence of a pandemic; in the presence of the pandemic, they may resort to alternative communication modalities, as they appeared to do in our study, albeit with some uncertainty as to whether the process, or quality associated with these modalities meet the desired outcomes that are associated with conventional in-person communication. There are many reports of moral distress in physicians and nurses during the pandemic; caring for patients dying alone without any family present is cited as a major contributor to this.[34-37] For hospital administrative policy development, there is the ethical challenge of balancing the patient and family need for in-person contact at end-of-life against the measures to reduce infection risk with COVID-19,[13 38] in addition to legal considerations.[38]

Study strengths and limitations

There were no missing data in a decedent cohort that was representative of the regional source population in all acute care hospitals. Although cohort groups were effectively matched, the matching was limited to age, sex and care service, and other baseline differences could have existed. We acknowledge that many of the early COVID-19 pandemic deaths occurred in nursing home or long-term care facilities, and our study findings may have limited generalizability in relation to such settings. Other limitations include the retrospective nature of the study, absence of a qualitative assessment of communication encounters, absence of abstractor blinding and the possibility of misclassification bias in data abstraction, which could have occurred despite rigorous training and data accuracy checks.

Conclusions

In hospitalized COVID-19 pandemic Wave 1 decedents, families' physical presence and in-person healthcare team-family communication encounters were markedly reduced at end-of-life; virtual modalities were adopted to a limited extent, more so in patient-family than healthcare team-family encounters, and telephone use was increased in healthcare team-family communications. Although allied health interprofessional team members had lesser involvement intra-pandemically in those dying of COVID-19 infection, spiritual care and palliative care

involvement was maintained at just below pre-pandemic levels. Future studies are required to examine the implications of the pandemic-related communication changes for the patient, the family, and the healthcare team.

Data availability statement

No additional data are available.

Acknowledgments

The authors are grateful to Dong Vo, Ottawa Methods Centre's Data Management Services and Ottawa Hospital Research Institute for the creation of an electronic study database, and to Dr Tim Ramsay, Scientific Director, Ottawa Methods Centre and Senior Scientist, Ottawa Hospital Research Institute for his statistical advice. We gratefully acknowledge the input of representatives from Bereaved Families of Ontario, Canadian Virtual Hospice and the Champlain Hospice Palliative Care Program.

Contributors

JD conceptualized the project and designed the study with assistance from PL, HP, LC, VG, RM, GW, AB, KW, JL, CW, DB, PE, ID, KB, CD, AI, SHB, SI, PT, BV. The study site leads, HP, VG, LC, co-ordinated ethics applications along with PL, JL and DB. Data were abstracted by PL, HP, SRA, EB, LC, RM, GW, AB, KAM, KW, PE, ID, KB and CD. Data verification was coordinated by PL with the assistance of HP, SRA, EB, LC, RM, GW, AB, PE and KB. Statistical analyses were performed by PL and CW. All authors, including MK, CN, BH and KA assisted with data interpretation. The original version of the manuscript was drafted by PL and critically reviewed by all authors. All authors approved the final manuscript as submitted.

Funding

This work has been funded in part by a grant from the University of Ottawa Faculty of Medicine COVID-19 Pandemic Response Funding Program, and in part by a contribution from Health Canada, Health Care Policy and Strategies Program. The views expressed herein do not necessarily represent the views of Health Canada nor the University of Ottawa.

Competing interests

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

References

1. Huang C, Wang Y, Li X, et al. Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China. *Lancet (London, England)* 2020;395(10223):497-506. doi: 10.1016/s0140-6736(20)30183-5 [published Online First: 2020/01/28]

2. World Health Organisation. WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020 2020 [Available from: https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020 accessed 27/12/2021 2021.

3. Docherty AB, Harrison EM, Green CA, et al. Features of 20 133 UK patients in hospital with covid-19 using the ISARIC WHO Clinical Characterisation Protocol: prospective observational cohort study. *BMJ (Clinical research ed)* 2020;369:m1985. doi: 10.1136/bmj.m1985 [published Online First: 2020/05/24]

4. Murthy S, Archambault PM, Atique A, et al. Characteristics and outcomes of patients with COVID-19 admitted to hospital and intensive care in the first phase of the pandemic in Canada: a national cohort study. *CMAJ open* 2021;9(1):E181-e88. doi: 10.9778/cmajo.20200250 [published Online First: 2021/03/11]

5. Petrilli CM, Jones SA, Yang J, et al. Factors associated with hospital admission and critical illness among 5279 people with coronavirus disease 2019 in New York City: prospective cohort study. *BMJ (Clinical research ed)* 2020;369:m1966. doi: 10.1136/bmj.m1966 [published Online First: 2020/05/24]

6. Radbruch L, De Lima L, Knaul F, et al. Redefining Palliative Care-A New Consensus-Based Definition. *Journal of Pain and Symptom Management* 2020;60(4):754-64. doi: 10.1016/j.jpainsymman.2020.04.027 [published Online First: 2020/05/11]

7. Selman LE, Brighton LJ, Sinclair S, et al. Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries. *Palliative Medicine* 2018;32(1):216-30. doi: 10.1177/0269216317734954 [published Online First: 2017/10/13]

8. World Health Organization. WHO Palliative Care 2002 [Available from: https://www.who.int/health-topics/palliative-care accessed 27/12/2021.

9. Hanna JR, Rapa E, Dalton LJ, et al. A qualitative study of bereaved relatives' end of life experiences during the COVID-19 pandemic. *Palliative Medicine* 2021;35(5):843-51. doi: 10.1177/02692163211004210 [published Online First: 2021/04/01]

10. Mayland CR, Hughes R, Lane S, et al. Are public health measures and individualised care compatible in the face of a pandemic? A national observational study of bereaved relatives' experiences during the COVID-19 pandemic. *Palliative Medicine* 2021;35(8):1480-91. doi: 10.1177/02692163211019885 [published Online First: 2021/06/01]

11. Schloesser K, Simon ST, Pauli B, et al. "Saying goodbye all alone with no close support was difficult"- Dying during the COVID-19 pandemic: an online survey among bereaved relatives about end-of-life care for patients with or without SARS-CoV2 infection. *BMC Health Services Research* 2021;21(1):998. doi: 10.1186/s12913-021-06987-z [published Online First: 2021/09/24]

12. Kentish-Barnes N, Chaize M, Seegers V, et al. Complicated grief after death of a relative in the intensive care unit. *The European Respiratory Journal* 2015;45(5):1341-52. doi: 10.1183/09031936.00160014 [published Online First: 2015/01/24]

13. Downar J, Kekewich M. Improving family access to dying patients during the COVID-19 pandemic. *The Lancet Respiratory Medicine* 2021;9(4):335-37. doi: 10.1016/s2213-2600(21)00025-4 [published Online First: 2021/01/16]

14. Fiest KM, Krewulak KD, Hiploylee C, et al. An environmental scan of visitation policies in Canadian intensive care units during the first wave of the COVID-19 pandemic. *Canadian Journal of Anaesthesia = Journal*

Canadien D'anesthesie 2021;68(10):1474-84. doi: 10.1007/s12630-021-02049-4 [published Online First: 2021/07/02]

15. Moss SJ, Krewulak KD, Stelfox HT, et al. Restricted visitation policies in acute care settings during the COVID-19 pandemic: a scoping review. *Critical Care (London, England)* 2021;25(1):347. doi: 10.1186/s13054-021-03763-7 [published Online First: 2021/09/27]

16. Kentish-Barnes N, Cohen-Solal Z, Morin L, et al. Lived Experiences of Family Members of Patients With Severe COVID-19 Who Died in Intensive Care Units in France. *JAMA Netw Open* 2021;4(6):e2113355. doi: 10.1001/jamanetworkopen.2021.13355 [published Online First: 2021/06/22]

17. Connellan D, Diffley K, McCabe J, et al. Documentation of Do-Not-Attempt-Cardiopulmonary-Resuscitation orders amid the COVID-19 pandemic. *Age and Ageing* 2021;50(4):1048-51. doi: 10.1093/ageing/afab075 [published Online First: 2021/04/29]

18. Reidy J, Savageau JA, Sullivan K, et al. Assessing Goals-of-Care Documentation during the COVID-19 Patient Surge in an Academic Safety-Net Medical Center. *Journal of Palliative Medicine* 2021 doi: 10.1089/jpm.2021.0172 [published Online First: 2021/08/18]

19. Martinsson L, Bergström J, Hedman C, et al. Symptoms, symptom relief and support in COVID-19 patients dying in hospitals during the first pandemic wave. *BMC Palliative Care* 2021;20(1):102. doi: 10.1186/s12904-021-00785-4 [published Online First: 2021/07/03]

20. Strang P, Bergström J, Martinsson L, et al. Dying From COVID-19: Loneliness, End-of-Life Discussions, and Support for Patients and Their Families in Nursing Homes and Hospitals. A National Register Study. *Journal of Pain and Symptom Management* 2020;60(4):e2-e13. doi: 10.1016/j.jpainsymman.2020.07.020 [published Online First: 2020/07/30]

21. von Elm E, Altman DG, Egger M, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *PLoS Medicine* 2007;4(10):e296. doi: 10.1371/journal.pmed.0040296 [published Online First: 2007/10/19]

22. Government of Ontario. COVID-19 case numbers and spread [Available from: https://covid-19.ontario.ca/data/case-numbers-and-spread accessed 27/12/2021.

23. Piscitello GM, Fukushima CM, Saulitis AK, et al. Family Meetings in the Intensive Care Unit During the Coronavirus Disease 2019 Pandemic. *Am J Hosp Palliat Care* 2021;38(3):305-12. doi: 10.1177/1049909120973431 [published Online First: 2020/11/20]

24. Pastor-Barriuso R, Pérez-Gómez B, Hernán MA, et al. Infection fatality risk for SARS-CoV-2 in community dwelling population of Spain: nationwide seroepidemiological study. *BMJ (Clinical research ed)* 2020;371:m4509. doi: 10.1136/bmj.m4509 [published Online First: 2020/11/29]

25. Hugelius K, Harada N, Marutani M. Consequences of visiting restrictions during the COVID-19 pandemic: An integrative review. *International Journal of Nursing Studies* 2021;121:104000. doi: 10.1016/j.ijnurstu.2021.104000 [published Online First: 2021/07/10]

26. Wakam GK, Montgomery JR, Biesterveld BE, et al. Not Dying Alone - Modern Compassionate Care in the Covid-19 Pandemic. *The New England Journal of Medicine* 2020;382(24):e88. doi: 10.1056/NEJMp2007781 [published Online First: 2020/04/15]

27. Pun BT, Badenes R, Heras La Calle G, et al. Prevalence and risk factors for delirium in critically ill patients with COVID-19 (COVID-D): a multicentre cohort study. *The Lancet Respiratory Medicine* 2021;9(3):239-50. doi: 10.1016/s2213-2600(20)30552-x [published Online First: 2021/01/12]

28. Rose L, Yu L, Casey J, et al. Communication and Virtual Visiting for Families of Patients in Intensive Care during the COVID-19 Pandemic: A UK National Survey. *Annals of the American Thoracic Society* 2021;18(10):1685-92. doi: 10.1513/AnnalsATS.202012-1500OC [published Online First: 2021/02/23]

29. Bloomer MJ, Walshe C. Smiles behind the masks: A systematic review and narrative synthesis exploring how family members of seriously ill or dying patients are supported during infectious disease outbreaks. *Palliative Medicine* 2021;35(8):1452-67. doi: 10.1177/02692163211029515 [published Online First: 2021/08/19]

30. Selman LE, Chao D, Sowden R, et al. Bereavement Support on the Frontline of COVID-19: Recommendations for Hospital Clinicians. *Journal of Pain and Symptom Management* 2020;60(2):e81-e86. doi: 10.1016/j.jpainsymman.2020.04.024 [published Online First: 2020/05/08]

31. Cherniwchan HR. Harnessing New and Existing Virtual Platforms to Meet the Demand for Increased Inpatient Palliative Care Services During the COVID-19 Pandemic: A 5 Key Themes Literature Review of the

Characteristics and Barriers of These Evolving Technologies. *Am J Hosp Palliat Care* 2021:10499091211036698. doi: 10.1177/10499091211036698 [published Online First: 2021/08/07]

32. Kennedy NR, Steinberg A, Arnold RM, et al. Perspectives on Telephone and Video Communication in the Intensive Care Unit during COVID-19. *Annals of the American Thoracic Society* 2021;18(5):838-47. doi: 10.1513/AnnalsATS.202006-729OC [published Online First: 2020/11/13]

33. Mercadante S, Adile C, Ferrera P, et al. Palliative Care in the Time of COVID-19. *Journal of Pain and Symptom Management* 2020;60(2):e79-e80. doi: 10.1016/j.jpainsymman.2020.04.025 [published Online First: 2020/05/08]

34. McMillan K, Wright DK, McPherson CJ, et al. Visitor Restrictions, Palliative Care, and Epistemic Agency: A Qualitative Study of Nurses' Relational Practice During the Coronavirus Pandemic. *Glob Qual Nurs Res* 2021;8:23333936211051702. doi: 10.1177/23333936211051702 [published Online First: 2021/11/12]

35. Villa M, Balice-Bourgois C, Tolotti A, et al. Ethical Conflict and Its Psychological Correlates among Hospital Nurses in the Pandemic: A Cross-Sectional Study within Swiss COVID-19 and Non-COVID-19 Wards. *Int J Environ Res Public Health* 2021;18(22) doi: 10.3390/ijerph182212012 [published Online First: 2021/11/28]

36. Anderson-Shaw LK, Zar FA. COVID-19, Moral Conflict, Distress, and Dying Alone. *Journal of Bioethical Inquiry* 2020;17(4):777-82. doi: 10.1007/s11673-020-10040-9 [published Online First: 2020/11/11]

37. Cook DJ, Takaoka A, Hoad N, et al. Clinician Perspectives on Caring for Dying Patients During the Pandemic : A Mixed-Methods Study. *Annals of Internal Medicine* 2021;174(4):493-500. doi: 10.7326/m20-6943 [published Online First: 2020/12/08]

38. Sudai M. Not Dying Alone: the Need to Democratize Hospital Visitation Policies During Covid-19. *Med Law Rev* 2021;29(4):613-38. doi: 10.1093/medlaw/fwab033 [published Online First: 2021/09/14]

FIGURE TITLES

Figure 1. Study flow diagram of study group derivation, exposures, matching and outcomes

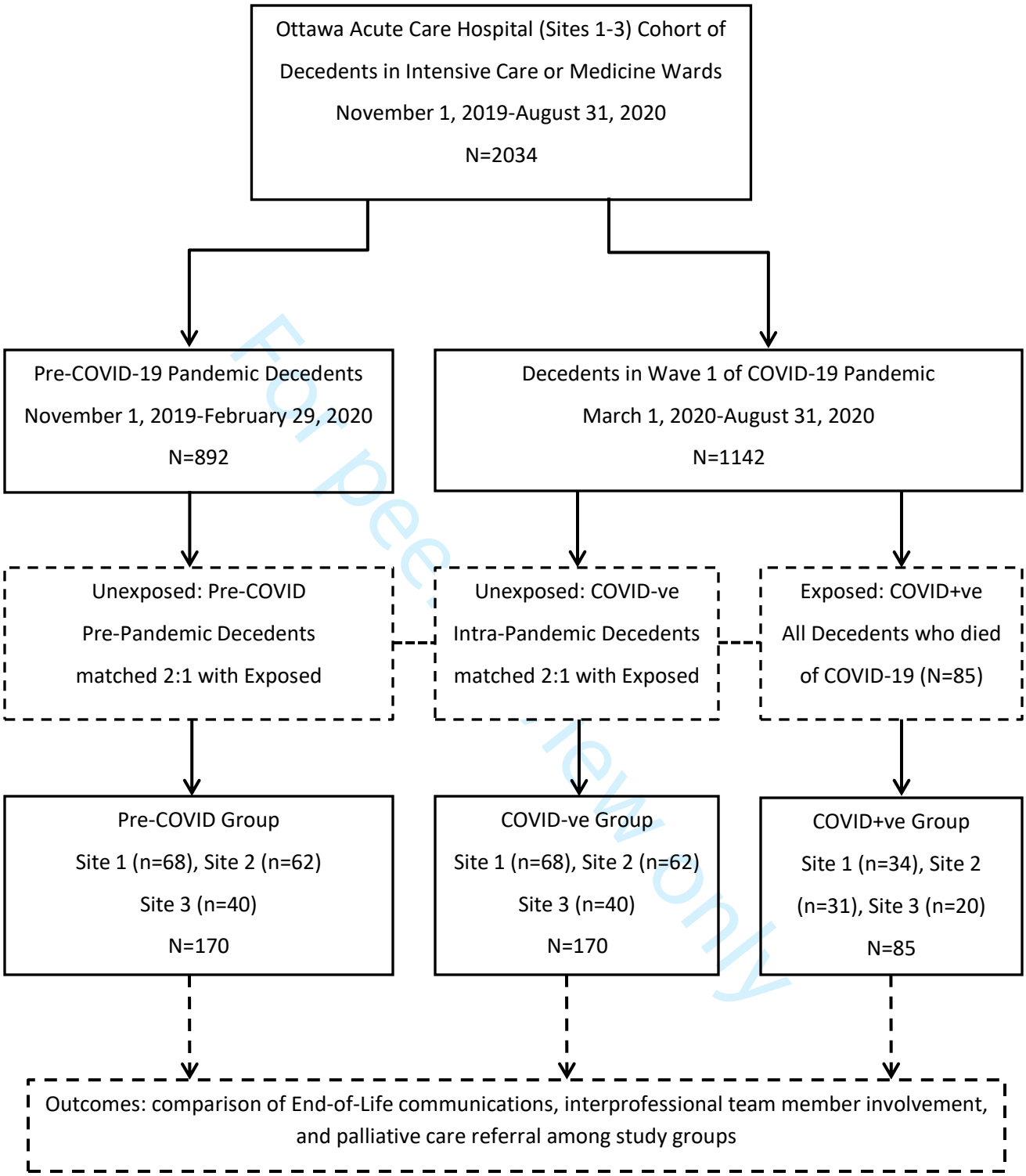
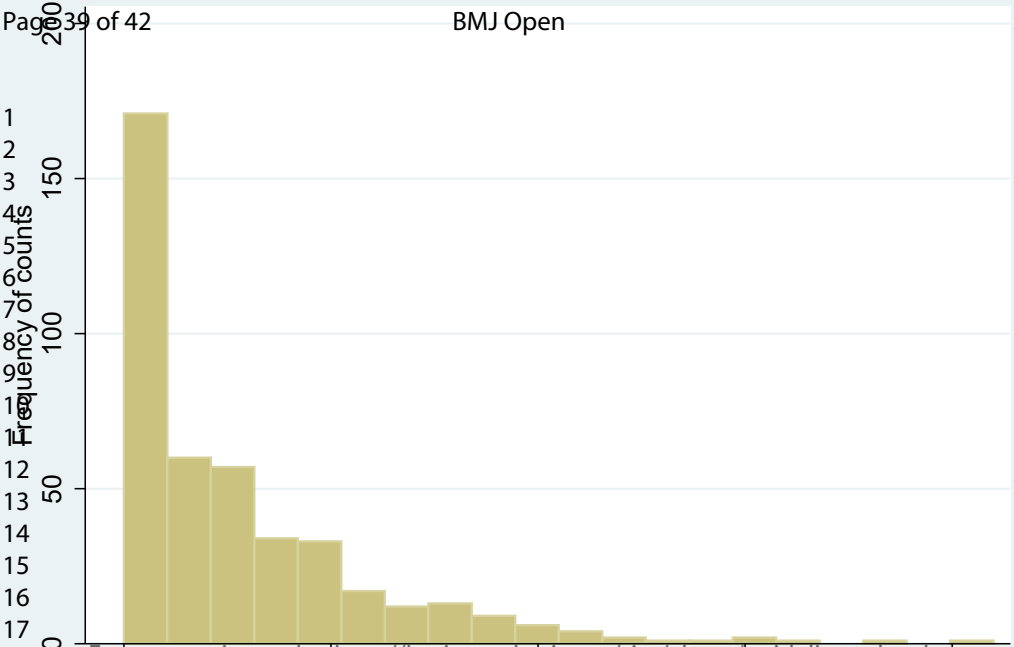
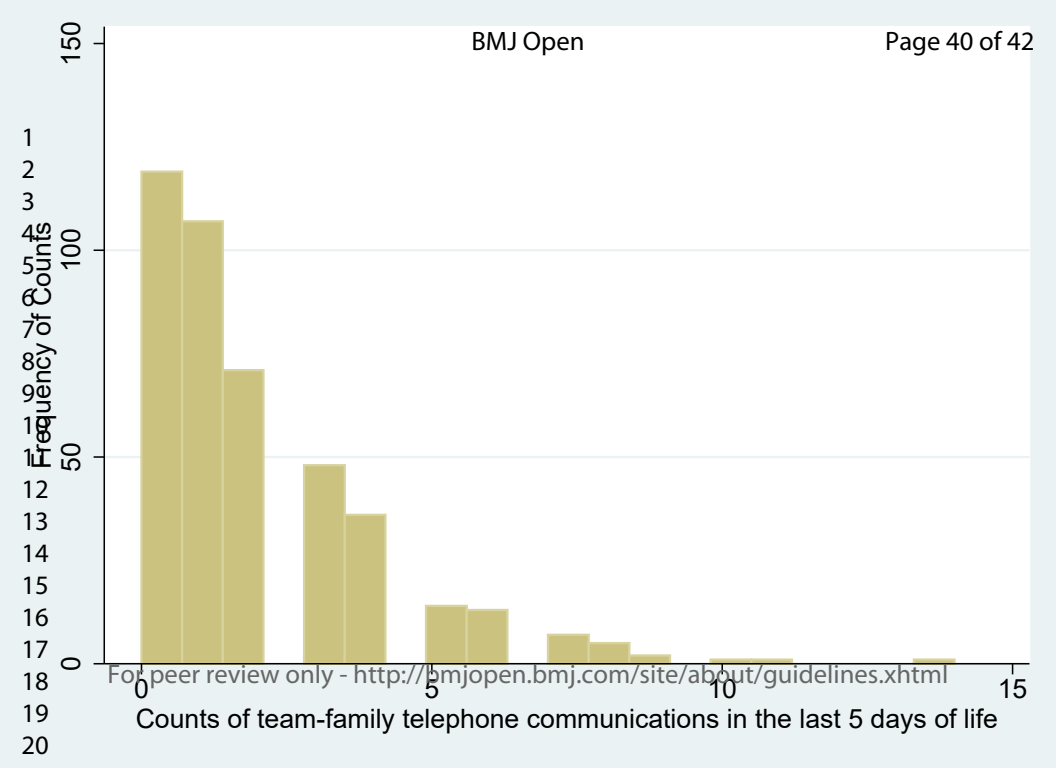


Figure 1 Study Flow Diagram of Study Group Derivation, Exposures, Matching and Outcomes





Appendix 3 Healthcare team-family virtual communication encounters in the last 5 days of life and variables examined in logistic regression analyses restricted to COVID-ve and COVID+ve groups

Virtual communication encounters and variables examined	Proportion of patients* (%)	Unadjusted OR (95% CI)		P value		Adjusted OR (95% CI)		P value
Occurrence: one or more	27/255 (10.6)							
Age of decedent$	…	0.99	(0.96-1.02)	0.340		0.995	(0.96-1.04)	0.808
Sex of decedent								
Female	9/105 (8.6)	1				1		
Male	18/150 (12.0)	1.46	(0.63-3.38)	0.383		1.35	(0.55-3.32)	0.516
Study group†								
COVID-ve	10/170 (5.9)	**1**				**1**		
COVID+ve	17/85 (20.0)	**4.00**	**(1.74-9.18)**	**0.001**		**3.68**	**(1.51-8.95)**	**0.004**
Hospital site								
Site 1	15/102 (14.71)	**1**				1		
Site 2	**5/93 (5.4)**	**0.33**	**(0.12-0.95)**	**0.039**		0.32	(0.10-1.02)	0.053
Site 3	7/60 (11.7)	0.77	(0.29-2.00)	0.586		0.79	(0.28-2.21)	0.649
Care service at death								
Medicine	**15/184 (8.2)**	**1**				1		
Intensive Care Unit	**12/71 (16.9)**	**2.29**	**(1.01-5.18)**	**0.046**		1.92	(0.69-5.37)	0.213
Admission duration$	…	0.997	(0.98-1.01)	0.697		0.997	(0.98-1.02)	0.747

Family present in-person								
Yes	15/175 (8.6)	1				1		
No	12/80 (15.0)	1.88	(0.84-4.23)	0.126		1.61	(0.63-4.10)	0.319

*Proportion of patients = proportion of total number for each categorical variable; OR = Odds Ratio;

$Treated as a continuous variable or covariate

†Pre-COVID group were excluded from the bivariable and multivariable analyses

STROBE Statement—Checklist of items that should be included in reports of ***cohort studies***

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	9-10
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	12
Objectives	3	State specific objectives, including any prespecified hypotheses	12-13
Methods			
Study design	4	Present key elements of study design early in the paper	13
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	13-14
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up (*b*) For matched studies, give matching criteria and number of exposed and unexposed	14
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	14-15
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	14
Bias	9	Describe any efforts to address potential sources of bias	15
Study size	10	Explain how the study size was arrived at	15-16
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	16
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding (*b*) Describe any methods used to examine subgroups and interactions (*c*) Explain how missing data were addressed (*d*) If applicable, explain how loss to follow-up was addressed (*e*) Describe any sensitivity analyses	16
Results			
12Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	16-17
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) Summarise follow-up time (eg, average and total amount)	16-18
Outcome data	15*	Report numbers of outcome events or summary measures over time	18-25

Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (*b*) Report category boundaries when continuous variables were categorized (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	18-25
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA
Discussion			
Key results	18	Summarise key results with reference to study objectives	25-29
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	28
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	25-29
Generalisability	21	Discuss the generalisability (external validity) of the study results	25-29
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	29-30

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at http://www.strobe-statement.org.